The Law Commission

Consultation Paper No. 129

Mentally Incapacitated Adults and Decision-Making

Medical Treatment and Research

HMSO

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This consultation paper, completed on 18 March 1993, is circulated for comment and criticism only and does not represent the final views of the Law Commission.

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THE LAW COMMISSION

CONSULTATION PAPER No. 129

MENTALLY INCAPACITATED ADULTS AND DECISION-MAKING: MEDICAL TREATMENT AND RESEARCH

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PART I

INTRODUCTION

1.1 In April 1991 the Law Commission published a preliminary Consultation Paper, Mentally Incapacitated Adults and Decision-Making : An Overview.[1] Its object was to assess the extent of the need for reform and the most practicable way forward in a difficult and diffuse area. To date over 120 responses have been received. We have also held valuable meetings with several groups of interested organisations and individuals. In September 1991 the Scottish Law Commission also published a Discussion Paper on Mentally Disabled Adults.[2] The main criticisms of the present law in Scotland reflect concerns very similar to those identified in England and Wales.[3] We are now embarking on a second round of consultation in which we shall canvass more precise and detailed provisional proposals for reform.

1.2 Our initial consultations convinced us that there is a need for some reform. We decided that the best way of taking the project forward is by a series of separate consultations on particular topics, the results of which could either be combined into a single overall framework or implemented separately. Those topics can be roughly characterised as (1) the "private" law, (2) the public law, and (3) the medical law. In Consultation Paper No.128[4] we set out provisional proposals for the establishment of a new "private law" jurisdiction to be available for the resolution of disputes or uncertainties which may arise between individuals in relation to an incapacitated person's personal care. Decisions about the person's medical treatment were not considered. In this paper we explore the idea of a similar legal

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1 Mentally Incapacitated Adults and Decision-Making: An Overview (1991), Consultation Paper No. 119.

2 Mentally Disabled Adults: Legal Arrangements for Managing their Welfare and Finances (1991), Discussion Paper No. 94.

3 A number of options for reform are proposed by the Scottish Law Commission, including the creation of a statutory "personal guardian" empowered to take personal welfare decisions on behalf of a disabled person and a new statutory system of financial management.

4 Mentally Incapacitated Adults and Decision-Making: A New Jurisdiction (1993).

machinery whereby substitute decisions about medical treatment could be authorised at an appropriate level. We also explore the creation of a jurisdiction to decide on the scope and validity of decisions made by the incapacitated person before the onset of incapacity. The public law paper will consider the powers of compulsory intervention available to public authorities, principally in order to protect incapacitated, and possibly also vulnerable, people from harm. As in Consultation Paper No.128, for the purposes of discussion we have put forward a number of proposals for change but, of course, these are entirely provisional and we would welcome all comments, criticisms and alternative suggestions.

1.3 The issues discussed in this paper came to prominence following the *Re F* decision in 1989.[5] The House of Lords decided that if an adult lacks the capacity to consent to medical treatment there is no person or court who can give consent on the incapable person's behalf. Court involvement is possible through the making of a declaration that a proposed course of action either would, or would not, be lawful in the circumstances and this procedure has been used in a series of reported cases.[6] However, because of the limitations of the declaration procedure, there have been a number of calls for the revival of a "parens patriae" jurisdiction to allow the courts to exercise the same discretion in relation to the medical treatment of an incapacitated adult, which is available under the inherent jurisdiction of the High Court in relation to children.[7] In Consultation Paper No.119, we noted that there would be serious difficulties in recreating this prerogative jurisdiction, particularly because of the repeal of the legislation which regulated the exercise of the powers.[8] It would be necessary to establish a test to identify those to whom the jurisdiction would apply, the extent of the powers which

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5 *Re F (Mental Patient: Sterilisation)* [1990] 2 A.C. 1. Earlier cases concerned with the medical treatment of incapacitated adults included *Re T* (unreported), Latey J., 14 May 1987; *Re X, The Times*, 4 June 1987; *T* v. *T and Another* [1988] Fam. 52.

6 Cases decided since *Re F* include: *Re SG (Adult Mental Patient: Abortion)* [1991] 2 F.L.R. 329; *Re GF (Medical Treatment)* [1992] 1 F.L.R. 293; *Re H (Mental Patient: Diagnosis)* [1993] 1 F.L.R. 28; *Re T (Adult: Refusal of Treatment)* [1992] 3 W.L.R. 782; and *Airedale NHS Trust* v. *Bland* [1993] 2 W.L.R. 316.

7 The first of these was by Wood J. in *T* v. *T* [1988] Fam. 52, 68, and the most recent was by Lord Lowry in *Airedale NHS Trust* v. *Bland* [1993] 2 W.L.R. 316, 378. In the same case, Lord Goff, at p.365, referred to the reluctance with which the House of Lords came to the conclusion, in *Re F* [1990] 2 A.C. 1, that the jurisdiction no longer existed.

8 Paragraphs 3.35-3.36.

would be available, and the situations when treatment could be carried out without seeking court approval. There appears to be a need for a jurisdiction designed to suit modern conditions. The urgency and importance of this need was revealed by the cases which occurred while this paper was being prepared, and particularly by the decision of the House of Lords in *Airedale NHS Trust* v. *Bland*.[9]

Aims of reform

1.4 The policy aims set out in Consultation Paper No.119 were supported by many respondents and remain the basis of our approach:

(i) that people should be enabled and encouraged to take for themselves those decisions which they are able to take;

(ii) that where it is necessary in their own interests or for the protection of others that someone else should take decisions on their behalf, the intervention should be as limited as possible and concerned to achieve what the person himself would have wanted; and

(iii) that proper safeguards should be provided against exploitation, neglect, and physical, sexual or psychological abuse.[10]

1.5 It is implicit in the aim of "limited" intervention that any substitute decisions should be taken at the lowest appropriate level and with the least possible procedural formality. Our responses revealed very little support for any statutory arrangements which would require

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[9] [1993] 2 W.L.R. 316. There were calls by Lord Browne-Wilkinson, at p.382, and by Lord Mustill, at p.392, for Parliament to address the issues raised by the case. A Select Committee of the House of Lords on Medical Ethics has been appointed to consider:

> "the ethical, legal and clinical implications of a person's right to withhold consent to life-prolonging treatment, and the position of persons who are no longer able to give or withhold consent; and to consider whether and in what circumstances actions that have as their intention or a likely consequence the shortening of another person's life may be justified on the grounds that they accord with that person's wishes or with that person's best interests; and in all the foregoing considerations to pay regard to the likely effects of changes in law or medical practice on society as a whole." (HL Paper 67)

[10] Consultation Paper No.119, para. 4.27.

every mentally incapacitated adult to be in some way identified, labelled and provided with a continuing substitute decision-maker. Many decisions can and should be taken without formal appointment or approval, but some will always have to be taken by some form of judicial body operating a judicial procedure. The aim is that the decision be taken at the lowest level which is consistent with the protection of the client both from the improper usurpation of his autonomy and from improper decision-making.

1.6 It has been said that the law should be readily intelligible to and applicable by all those who undertake the care of persons lacking the capacity to consent to treatment.[11] The complexity and uncertainty of the current law was one reason why reform was supported by respondents to Consultation Paper No.119. It has been suggested that doctors and dentists may refuse to carry out treatment because of uncertainty about its lawfulness.[12] It might have been thought that this concern would decrease after the decision of the House of Lords in *Re F*[13] but it was raised by a number of respondents. The law cannot attempt to dictate the solution in every case but, so far as possible in such a difficult area, any new statutory system should describe with clarity what those who are affected by it may or may not do without obtaining prior authority from others.

1.7 In *Re F* Lord Brandon was concerned that patients who lack the capacity to take decisions about their own medical treatment should not be deprived of medical care "which they need and to which they are entitled".[14] The same concern was present in the other speeches. Lord Jauncey said that the law must not convert incapacitated patients into second class citizens for the purposes of health care, depriving them of treatment which capable persons could reasonably expect to receive in similar circumstances.[15] We agree, and we

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[11] *Re F* [1990] 2 A.C. 1, 52 *per* Lord Bridge.

[12] Report of the Working Party on the Legal, Medical and Ethical Issues of Mental Handicap of the Royal Society for Mentally Handicapped Children and Adults (the Mencap working party), *Competency and Consent to Medical Treatment* (1989), p.3.

[13] [1990] 2 A.C. 1.

[14] *Ibid.*, at p.55.

[15] *Ibid.*, at p.83.

recognise the importance of not erecting such onerous legal requirements or procedural safeguards that the patient's care suffers.

1.8 However, in the same case, Lord Donaldson M.R. in the Court of Appeal emphasised the special status of the incapable patient. The ability of the capable adult patient to exercise a free choice in deciding whether to accept or to refuse medical treatment and to choose between treatments was a crucial factor and could not be dismissed as desirable but inessential. If it was necessarily absent there must be a greater caution in deciding whether to treat and, if so, how to treat.[16] There is a fundamental tension in this area between the need to allow professionals scope to do their best for their patients, and the need to protect those who cannot protect themselves from treatment, however well-intentioned, which they may not want or need. The law must attempt to find a balance between these considerations.

1.9 There is also a danger that those who are unable to request treatment will never be offered it, particularly where resources are scarce. A patient's family or an "advocate" may have an important role to play in drawing attention to a patient's rights and needs.[17] The role of the courts in this area is, however, necessarily limited. Lord Donaldson M.R. has suggested that it would be an abuse of a court's powers to order a doctor to adopt a course of treatment which in his bona fide clinical opinion is not in the best interests of the patient.[18] Doctors can refuse to adopt a treatment which is medically contra-indicated or which they could not conscientiously administer for some other reason.[19] Furthermore, Balcombe L.J. has referred to the "absolute undesirability" of a court compelling the provision of scarce resources to a particular patient, without knowing whether there are other patients to whom those resources might more advantageously be devoted.[20]

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16 *Ibid.*, at pp.18-19.

17 L. Gostin in C. Dyer (ed.), *Doctors, Patients and the Law* (1992), pp.86-87.

18 *Re J (A Minor) (Child in Care: Medical Treatment)* [1993] Fam. 15, 26-27.

19 *Re J (A Minor) (Wardship: Medical Treatment)* [1991] Fam. 33, 41 *per* Lord Donaldson M.R.

20 *Re J* [1993] Fam. 15, 30.

The scope of the paper

1.10 Throughout this paper "medical treatment" is used in a wide sense to include surgical, medical or dental treatment, any procedure undertaken for the purpose of diagnosis,[21] and any procedure (including the administration of an anaesthetic) which is ancillary to such treatment.[22] As in the Mental Health Act 1983[23] the expression also includes nursing, and care, habilitation and rehabilitation under medical supervision.

1.11 The main focus of this paper is on those treatments which would be tortious (and also criminal) in the absence of the consent of a patient who has the capacity to give consent. Psychological treatments do not fall into this category but can nevertheless interfere with patients' basic rights.[24] There may be other forms of treatment, such as the prescription of drugs which the person takes himself, which cannot be characterised as battery since the tort of battery involves a direct application of force.[25] Although such treatment cannot amount to an unlawful battery, its administration in the absence of a proper legal justification will constitute a breach of duty properly characterised as negligence if harm is suffered as a result. Such treatments may be justifiable where the patient is incapacitated, but the principles governing their use should be the same as those applied to the use of more physically invasive treatments.

1.12 The expression "treatment provider" is used to describe anyone providing medical treatment. As well as doctors, this expression includes dentists, and nurses and other professionals, and also those without medical qualifications such as family members or care workers administering prescribed medication, or non-prescription remedies. Of course, the law of negligence will be applicable to any person who attempts a treatment which is beyond

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[21] For the common law position in relation to the carrying out of invasive diagnostic procedures on an adult incapable of consenting, see *Re H (Mental Patient: Diagnosis)* [1993] 1 F.L.R. 28.

[22] As in s.8 of the Family Law Reform Act 1969.

[23] Section 145(1).

[24] See the *Code of Practice* prepared under s.118 of the Mental Health Act 1983, para. 19.1.

[25] *Letang* v. *Cooper* [1965] 1 Q.B. 232.

his or her competence, and there are certain functions which can only be performed by those with particular qualifications.

1.13 This paper is not concerned with the reform of the criminal law of homicide. A doctor, however well-intentioned, who does a positive act intended to end the life of a patient commits a serious criminal offence, even if the patient requests such steps.[26] Decisions made in relation to an incapable patient are constrained by the criminal law in the same way as the criminal law constrains the choices of a capable patient. However, capable patients are entitled to refuse any treatment, and doctors may withhold or withdraw treatment which is not in the best interests of their patient without being in breach of duty or in breach of the criminal law.[27] This is so even if death is the inevitable consequence. None of the proposals in this paper should be understood as sanctioning any conduct which is prohibited by the criminal law. However, to the extent that the proposals in this paper might alter what it would be reasonable for a person providing treatment to do, or what has been authorised by or on behalf of the person concerned, any criminal liability which is based upon a breach of a duty to the patient or a lack of authority would be affected.

The structure of the paper

1.14 The remainder of this paper will consider the shape which reform might take. The Mental Health Act 1983 applies only to treatments for mental disorder given to a small number of mentally disordered patients[28] (who may or may not have the capacity to give consent). The giving of most forms of treatment to most mentally incapacitated patients is governed largely by the principles of the common law. Guidance on the law and good practice is provided by the NHS Management Executive *Guide to Consent for Examination and Treatment* which was introduced in 1990 by Department of Health Circular HC(90)22;[29]

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[26] *R.* v. *Cox* (unreported), Ognall J., Winchester Crown Court, 18 September 1992, is a recent example.

[27] In *Airedale NHS Trust* v. *Bland* [1993] 2 W.L.R. 316, the House of Lords decided that the withholding or withdrawal of treatment was an omission rather than an act, and thus only a ground of criminal liability if in breach of a duty to the patient.

[28] See paras. 7.1-7.2 below.

[29] The "NHS *Guide to Consent*".

and by the *Code of Practice* prepared under section 118 of the Mental Health Act 1983.[30] The *Code of Practice* was published in May 1990 and a revised version is in preparation.[31] In addition, in October 1990, the Medical Ethics Committee and Mental Health Committee of the British Medical Association issued guidance for the medical profession on how to deal with the issues posed by the medical treatment of adults who are incapable of giving consent.[32]

1.15 The paper is arranged as follows. In Part II, we deal with the situation where doctors, and other treatment providers, are faced with a person who may not have the capacity to consent or refuse a particular treatment. We suggest a statutory formulation of the test of capacity to consent. Part III explores the basis upon which a treatment decision should be made once it is established that the person is incapable of making his own decision. We consider the relevance of decisions made by the incapacitated person before the onset of incapacity, and we suggest that the law should grant treatment providers an explicit but limited authority to take certain decisions after appropriate consultation. In Part IV, we consider a role for a judicial forum in resolving specific questions which may arise in relation to medical treatment and the appointment of individuals ("medical treatment proxies") to give or refuse consent to treatment on the incapacitated person's behalf. In Part V, we discuss a mechanism which might be available for the person concerned to appoint such an individual (a "medical treatment attorney") before he becomes incapacitated. In Part VI, we consider whether there are any situations which require the involvement of the judicial forum or an independent "second opinion". Finally, although it remains our intention not to re-open discussion upon the compulsory admission and treatment provisions in the Mental Health Act

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30 The "*Code of Practice*" is prepared "for the guidance of registered medical practitioners and members of other professions in relation to the medical treatment of patients suffering from mental disorder", Mental Health Act 1983, s.118(1)(b).

31 The *Code of Practice* is capable of providing guidance in relation to any medical treatment of patients suffering from mental disorder. However, it is in use principally among professionals working in the field of psychiatry. This paper is concerned with whether legal changes, which could not be achieved by a code of practice, are necessary or desirable.

32 *Medical Treatment and Incapable Adults: Interim Guidelines for the Medical Profession*. The "BMA *Interim Guidelines*".

1983,[33] Part VII considers the extent to which the treatment for mental disorder of mentally incapacitated people who are not subject to these provisions of the Act[34] might be included in the proposed system.

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[33] See Consultation Paper No.119, para. 1.17.

[34] With the exception of s.57 which applies to all patients, Part IV, Consent to Treatment, applies only to most, but not all, patients who are "liable to be detained" under the Act. See para. 7.2 below.

PART II

THE INCAPACITATED PATIENT

2.1 Lord Scarman has said that the right of a patient to determine for himself whether he will or will not accept medical treatment "may be seen as a basic human right protected by the common law".[1] A patient is entitled to reject a doctor's advice for reasons which are rational, or irrational or for no reason,[2] and a doctor who operates without the consent of his patient is guilty of the civil wrong of trespass to the person, and the criminal offence of assault.[3] More recently, it has been confirmed by the House of Lords that if a patient is capable of making a decision on whether to permit treatment and decides not to permit it his choice must be obeyed, even if on any objective view it is contrary to his best interests, and it is plain to all, including the patient, that adverse consequences and even death will or may ensue.[4]

2.2 Every adult is presumed to have the capacity to decide whether or not he will accept medical treatment, even if a refusal may risk permanent injury to his health or even lead to premature death, but this presumption is rebuttable.[5] The *Code of Practice* states that it is the personal responsibility of any doctor proposing to treat a patient to

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1 *Sidaway* v. *Board of Governors of the Bethlem Royal Hospital and Maudsley Hospital* [1985] A.C. 871, 882.

2 *Ibid.*, at p.904 *per* Lord Templeman.

3 *Ibid.*, at p.882 *per* Lord Scarman.

4 *Airedale NHS Trust* v. *Bland* [1993] 3 W.L.R. 316, 393 *per* Lord Mustill, and to similar effect see Lord Goff at p.367 and Lord Keith at p.360. Lord Donaldson M.R. has said that the only possible qualification to this otherwise absolute right would be where the patient's choice might lead to the death of a viable foetus. Such a case would, he said, be a novel problem of considerable legal and ethical complexity, *Re T* [1992] 3 W.L.R. 782, 786. No such exception was mentioned by the members of the House of Lords in *Airedale NHS Trust* v. *Bland*, and Lord Keith referred to patients who are conscious and "of sound mind" being *completely* at liberty to decline to undergo medical treatment, [1993] 2 W.L.R. 316, 360. See *Re S (Adult: Refusal of Treatment)* [1992] 3 W.L.R. 806, which was concerned with a child on the point of birth.

5 *Re T* [1992] 3 W.L.R. 782, 799 *per* Lord Donaldson M.R.

determine whether the patient has capacity to give a valid consent.[6] It may be both necessary and desirable to allow a doctor considerable discretion when making this judgment,[7] but his clinical judgment must be guided by current professional practice and subject to legal requirements.[8]

The definition of incapacity

2.3 The presence of a mental disorder does not necessarily mean that a patient is incapacitated[9] and whether or not a person has capacity is not a question of the degree of his intelligence or education.[10] Lord Brandon said in *Re F* that the test of capacity to consent is whether the patient is able to understand the nature or purpose of an operation or treatment[11], and the test used in the Mental Health Act 1983 is whether the patient is capable of understanding the "nature, purpose and likely effects" of the treatment.[12] This approach, usually referred to as a cognitive or "functional" test,[13] received a very great deal of support from our respondents, but there was concern that the test was neither clear nor widely understood. It was said that a patient who is regarded as mentally disordered may be assumed to be incapacitated without attempts being made to explain the proposed treatment or assess the person's understanding of that explanation. Legislation could clarify the legal test of capacity which should be applied. This test would also define the ambit of any statutory scheme to authorise

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6 *Code of Practice*, para. 15.14.

7 I. Kennedy in C. Dyer (ed.), *Doctors, Patients and the Law* (1992), pp.57-58.

8 *Code of Practice*, para. 15.14.

9 *Ibid.*, para. 15.10; NHS *Guide to Consent*, p.9. "It goes without saying that, unless clear statutory authority to the contrary exists, no one is to be detained in hospital or to undergo medical treatment or even to submit himself to a medical examination without his consent. That is as true of a mentally disordered person as of anyone else", *R.* v. *Hallstrom and another, ex p. W.*; *R.* v. *Gardner and another, ex p. L.* [1986] 1 Q.B. 1090, 1104 *per* McCullough J.

10 *Re T* [1992] 3 W.L.R. 782, 796 *per* Lord Donaldson M.R.

11 [1990] 2 A.C. 1, 55.

12 Sections 57(2)(a), 58(3)(b).

13 Consultation Paper No.119, para. 2.44.

decision-making at an appropriate level, and the supervisory jurisdiction of a judicial forum of some kind.

Should the presence of mental disorder be required?

2.4 In *Re F*, Lord Brandon said that the common law authority to provide treatment without consent applies to those who are incapable of giving consent to treatment "for whatever reason".[14] In Consultation Paper No.128, while recognising that the common law test of capacity is not explicitly concerned with mental disorder,[15] we suggested that too great a burden might be placed upon a test based solely on the *degree* of the patient's understanding.[16] We provisionally proposed that a threshold of mental disorder should be included in the test for incapacity[17] unless there is an inability to communicate.[18] We did not consider that this would cause any difficulties in relation to the matters considered in that paper, but different considerations may apply to the question of capacity to consent to medical treatment.

2.5 In *Re T*, the patient was undoubtedly incapacitated at the time that treatment was required because she was unconscious (and therefore incapable of communication). However, the issue was whether she had given a valid refusal of blood transfusions before losing consciousness. Lord Donaldson M.R. said that a person may lack capacity to give or refuse consent not only by reason of mental disorder but also because of temporary factors, such as confusion or shock, severe fatigue, pain or drugs being used in his treatment.[19] One or more of these features may be present in many cases of people who require medical treatment but whose own decisions should be respected. *Re T* was an extreme case in which pain, anxiety, pregnancy, illness, a recent car accident,

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[14] [1990] 2 A.C. 1, 55.

[15] Paragraph 3.9.

[16] Paragraph 3.11.

[17] Paragraph 3.14.

[18] Paragraph 3.41.

[19] [1992] 3 W.L.R. 782, 796.

and pain-killing and sedative drugs, all had a cumulative effect on the patient. The medical evidence about her understanding was contradictory and Lord Donaldson M.R. considered that there was abundant evidence to justify finding that she was not capable at the relevant time. In the event, it was not necessary to do so. Her decision was not a valid refusal of the treatment in question since it was not intended to apply to the extreme situation which had arisen,[20] or it was vitiated, either because the patient was misinformed about the consequences of the decision, or because of the "undue influence" of her mother.[21]

2.6 In some cases, the temporary effects of shock or an injury, or the influence of drugs, may give rise to an abnormal mental state which would qualify as "any other disability or disorder of mind" within the definition of mental disorder in section 1 of the Mental Health Act 1983. If a person is expressing a view, but is clearly not mentally disordered, we consider that the issue should be (as it was in *Re T*) whether or not that view represents a valid decision.[22] Therefore such a person might be included in a *declaratory* jurisdiction to determine questions of the scope or validity of a consent or refusal.[23] However, we tend to the view that a person who can express an apparent decision should not be included within a system to *authorise* the treatment of incapacitated patients without their consent, unless he suffers from a mental disorder.[24] We therefore provisionally propose that:

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[20] *Ibid.*, at pp.794-795 *per* Lord Donaldson M.R.

[21] *Ibid.*, at p.803 *per* Butler-Sloss L.J.

[22] The NHS *Guide to Consent* says that the patient's ability to appreciate the significance of information about a proposed treatment should be assessed where, for example, the patient may be shocked, distressed or in pain, or have difficulty in understanding English, or have impaired sight, or hearing or speech, p.3. Discussion of *incapacity* occurs only in the chapter dealing with "Consent by patients suffering from mental disorder", pp.9-11.

[23] See paras. 4.15-4.18 below.

[24] The prerogative powers which existed until 1959 were limited to those of "unsound mind" and it was not possible to appoint guardians with power under the Mental Health Act 1959 to consent to medical treatment unless the presence of mental disorder was established. See Consultation Paper No.119, paras. 3.2-3.5.

1. **Subject to proposal 4 below, a person should not be regarded as "incapacitated" unless it is established that he or she is suffering from a mental disorder as defined in section 1 of the Mental Health Act 1983.**[25]

2.7 It should be emphasised that a finding of mental disorder would only be the first stage in the assessment of capacity and the presumption of capacity would still apply. The "status" approach to capacity outlined in Consultation Paper No.119[26] received very little support from those who responded.

A cognitive, or function, test

2.8 English law requires that a patient knows "in broad terms" the nature and effect of the procedure to which consent (or refusal) is given and failure to provide further information, including information about the likely risks, does not vitiate the consent, although it may be a breach of the doctor's duty of care.[27] It has been argued that the ability to understand a "broad terms" explanation is all that is required for a person to give effective consent.[28] This might suggest that an ability to understand the principal risks associated with the treatment is not required, but current guidance advises professionals that a person who is incapable of understanding such risks should be regarded as incapacitated.[29]

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[25] Mental Health Act 1983, s.1(2), "'mental disorder' means mental illness, arrested or incomplete development of mind, psychopathic disorder and any other disorder or disability of mind." s.1(3) specifies that a person cannot be dealt with as suffering from mental disorder "by reason only of promiscuity or other immoral conduct, sexual deviancy or dependence on alcohol or drugs."

[26] Paragraph 2.43.

[27] *Chatterton* v. *Gerson* [1981] Q.B. 432; *Sidaway* [1985] A.C. 871.

[28] For example, M. Brazier, *Medicine, Patients and the Law* (2nd ed., 1992), p.101.

[29] *Code of Practice*, para. 15.15; BMA *Interim Guidelines*, p.3.

2.9 In Consultation Paper No.128 we proposed a formulation of a cognitive, or function, test which concentrates upon the person's ability to understand relevant "basic information".[30] The *Code of Practice* sets out what we consider to be useful guidance as to the "basic information" which is relevant to taking a decision about medical treatment. It suggests that, in order to have capacity, an individual must be able to:

> "-understand what medical treatment is and that somebody has said that he needs it and why the treatment is being proposed;
> -understand in broad terms the nature of the proposed treatment;
> -understand its principal benefits and risks;[31]
> -understand what will be the consequences of not receiving the proposed treatment".[32]

2.10 Phil Fennell has suggested that, instead of requiring an understanding of the anticipated consequences of a failure to treat, there should be an understanding and appreciation of "the likelihood that serious harm will result to his or her own health or safety or to the safety of others if he or she does not have the treatment".[33] He argues that, in this way, interference with a person's right to make his own decisions should be confined to cases where interference is necessary for the person's own health or safety or for the protection of others. We tend to think that this issue should be dealt with in the criteria for overriding an incapacitated patient's objections[34] rather than imported into the test of capacity.

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30 Paragraphs 3.19-3.24.

31 Although, as noted in para. 2.8 above, it is arguable that an ability to understand the principal risks is not required by the current law, it is certainly "information relevant to the decision". It appears that an understanding of possible side effects is required in the case of children, *Re R (A Minor) (Wardship: Consent to Treatment)* [1992] Fam. 11, 26.

32 Paragraph 15.15. The *Code of Practice* also suggests that the individual must "possess the capacity to make a choice". This additional requirement is considered in paras. 2.18-2.20 below.

33 "Informal Compulsion", [1992] J.S.W.F.L. 311, p.324.

34 See paras. 3.45 and 4.31-4.32 below.

2.11 In Consultation Paper No.128, we considered that only understanding "in broad terms" should be required and this approach is consistent with current law and practice in relation to medical treatment. It has been said judicially that a patient need not "understand the precise physiological process involved before he can be said to be capable of understanding the nature and likely effects of the treatment".[35] The BMA *Interim Guidelines* substantially reproduce the part of the *Code of Practice* already quoted,[36] but add that the ability to understand what medical treatment is, and the consequences of not receiving the proposed treatment, need only be "in broad terms".[37]

2.12 Adopting a test based upon understanding in broad terms of basic information, and adapting the test proposed in Consultation Paper No.128, we provisionally propose that:

> 2. **A mentally disordered person should be considered unable to take the medical treatment decision in question if he or she is unable to understand an explanation in broad terms and simple language of the basic information relevant to taking it, including information about the reasonably foreseeable consequences of taking or failing to take it, or is unable to retain the information for long enough to take an effective decision.**

2.13 If this proposal is adopted, it will mean that most people, even if their cognitive ability is limited, ought to be able to give a legally effective consent. This will give effect to their right to take decisions for themselves.[38] However, patients may

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[35] *R.* v. *Mental Health Act Commission, ex p. X.* (1992) 9 B.M.L.R. 77, 87 *per* Stuart-Smith L.J. Also reported as *R.* v. *Mental Health Act Commission, ex p. W., The Times*, 27 May 1988.

[36] See para. 2.9 above.

[37] Page 3.

[38] L. Gostin, *Mental Health Services - Law and Practice* (1986), para. 20.15.

understand enough to authorise their own treatment, but refuse to do so,[39] perhaps for reasons which are regarded as "irrational".

A rationality test?

2.14 Although there are references in *Re F* to capacity to make "rational decisions"[40] or "rationally" to form a wish not to be treated[41] it is clear that the law does not require that a patient's decisions be reasonable or based upon rational reasons.[42] The "outcome" approach to capacity, outlined in Consultation Paper No.119,[43] was not widely supported and in Consultation Paper No.128[44] we rejected a test of capacity based upon the ability to make "rational" decisions. In the context of medical treatment, we do not find the arguments for the introduction of a "rationality" requirement any more persuasive. We do not therefore propose it.

2.15 Professor Kennedy has argued that when a patient makes a choice "based on beliefs or values which are not generally accepted", the patient should be regarded as incapable if the beliefs are the product of a temporary delusion born of some current illness, but not if they are based on beliefs and values which a patient has long held and led his life by, even if they appear to others to be irrational. To treat the latter case as incapacity would rob the patient of his right to his own personality which may be far more serious and destructive than anything which could follow from the patient's decision in relation to a particular proposed treatment.[45] We would prefer not to concentrate upon the rationality or otherwise of a person's beliefs. Many beliefs or

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[39] M. Brazier, *Medicine, Patients and the Law* (2nd ed., 1992), p.102.

[40] [1990] 2 A.C. 1, 52 *per* Lord Bridge.

[41] *Ibid.*, at p.76 *per* Lord Goff.

[42] *Sidaway* [1985] A.C. 871, 904 *per* Lord Templeman. *Airedale NHS Trust* v. *Bland* [1993] 2 W.L.R. 316, 367 *per* Lord Goff.

[43] Paragraph 2.43.

[44] Paragraph 3.30.

[45] I. Kennedy in C. Dyer (ed.), *Doctors, Patients and the Law* (1992), pp.56-57.

value systems have little or no rational basis but we nevertheless respect people's rights to hold them, even to their own detriment. This is the reason why we maintain our provisional view that the issue should be whether the patient is capable of understanding information relevant to the decision. As Lord Donaldson M.R. has said, religious or other beliefs which bar particular kinds of medical treatment might be considered irrational by some, but a child who holds such beliefs may well have sufficient intelligence and understanding fully to appreciate the treatment proposed and the consequences of a refusal to accept that treatment.[46]

2.16 In Consultation Paper No.128 we doubted the need to stipulate that the fact that someone's decision differs from that which an ordinary prudent person would have taken is not, of itself, a sufficient basis for a finding of incapacity.[47] We invite views on whether it is necessary to do so in the context of medical decision-making. Under the current law, Lord Donaldson M.R. has said that, since the patient's right of choice exists whether the reasons for making that choice are rational, irrational, unknown or even non-existent, it is only relevant that his choice is contrary to what is to be expected of the vast majority of adults if there are other reasons for doubting his capacity to decide. The nature of his choice or the terms in which it is expressed may then tip the balance. The doctor should consider whether at the time when the decision was made the patient "had a capacity which was commensurate with the gravity of the decision which he purported to make". The more serious the decision, the greater should be the capacity required.[48] Lord Donaldson said that refusals can vary in importance. Some may involve a risk to life or of irreparable damage to health. Others may not.[49] It is certainly true that a patient will need to be given, and understand, more information before making some decisions than others, and that a doctor faced with a refusal which will have serious consequences should offer the patient more information. However, we have some difficulty with the idea that there should be a

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[46] *Re W (Medical Treatment: Court's Jurisdiction)* [1992] 3 W.L.R. 758, 769.

[47] Paragraph 3.25.

[48] *Re T* [1992] 3 W.L.R. 782, 796-797.

[49] *Ibid.*, at p.799.

"greater capacity" as opposed to an ability to understand more, or more significant, information. We do not consider that more than a "broad terms" understanding is required, since even the most serious refusals do not require an understanding of the "precise physiological process" by the capable adult patient.

Fluctuating understanding and temporary incapacity

2.17 Because a person's ability to understand may vary over time, the answer to a question whether or not a patient has capacity may depend upon the time at which that question is asked. Where the person's understanding is fluctuating or may improve in future, and treatment can safely be delayed, we consider that it would be appropriate to seek the patient's views and assess capacity when his understanding is at its best.[50] In *Re R*,[51] the issue was whether anti-psychotic drugs considered necessary by medical staff could be administered compulsorily to a 15-year-old girl. The Court of Appeal concluded that a child whose capacity varied from day to day could not have sufficient understanding and intelligence to give or withhold consent[52] even though at times she could make a "rational and informed decision".[53] It has been asked whether fluctuating understanding might constitute legal incapacity in the case of adults,[54] and it has been

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[50] Mental Health Act Commission, *Draft Code of Practice* (1985), para. 4.4.8. The fact that a child may or may not attain the capacity to decide for herself in future may have been an important factor in a number of cases concerning operations with "irreversible" consequences. Compare *Re D (A Minor) (Wardship: Sterilisation)* [1976] Fam. 185 and *Re B (A Minor) (Wardship: Sterilisation)* [1988] A.C. 199. Evidence about the reversibility of sterilisation operations may have decreased this concern, possibly unjustifiably. See *Re P (A Minor) (Wardship: Sterilization)* [1989] 1 F.L.R. 182.

[51] [1992] Fam. 11.

[52] *Ibid.*, at pp.25-26 *per* Lord Donaldson M.R.; at p.27 *per* Staughton L.J.; at p.32 *per* Farquharson L.J.

[53] *Ibid.* at p.27 *per* Staughton L.J. Lord Donaldson's statements in *Re R*, and the subsequent Court of Appeal judgment in *Re W (A Minor) (Medical Treatment: Court's Jurisdiction)* [1992] 3 W.L.R. 758, have attracted considerable criticism (for example, A. Grubb in A. Grubb (ed.), *Choices and Decisions in Health Care* (1993), pp.54-78). We do not intend to address those criticisms here. Much of the concern surrounds the question of whether a parent's consent continues to be effective once the child achieves capacity, and there is no such difficulty in relation to a capable adult.

[54] BMA, *Rights and Responsibilities of Doctors* (2nd ed., 1992), para. 8.4.1.

argued that the test for the capacity of a child must be the same as that for an adult.[55] However, Lord Donaldson M.R. has said that the decisions in *Re R* and *Re W* have no application to adult patients.[56] We consider that the test of capacity proposed in this paper should be concerned with the patient's ability to understand information at the time when the decision has to be made.[57]

A "true choice" test

2.18 The *Code of Practice* includes the requirement that in order to have capacity an individual must "possess the capacity to make a choice".[58] In a case concerning a child suffering from anorexia nervosa, Lord Donaldson M.R. said that although a patient may understand the treatment proposed and the consequences of failure to accept the treatment, certain conditions are capable of destroying the patient's ability to make an informed choice, creating a compulsion to refuse treatment or only to accept treatment which is likely to be ineffective.[59]

2.19 In Consultation Paper No.128 we proposed that people who have the ability to understand should be considered unable to take a decision if they are prevented by reason of mental disorder from the exercise of "independent will".[60] As well as including those who are subject to compulsions arising from their mental disorder itself, this was intended to include those whose mental disorders render them particularly susceptible to the influence of others. We invite comment on this approach in relation

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[55] P. Fennell [1992] J.S.W.F.L. 311, p.323; I. Kennedy, in C. Dyer (ed.), *Doctors, Patients and the Law* (1992), p.54.

[56] *Re T* [1992] 3 W.L.R. 782, 786.

[57] In *Re R*, Staughton L.J. emphasised that the case was not concerned with a one-off decision about a single treatment or surgical procedure, [1992] Fam. 11, 27. The recurrent provision of compulsory treatment for mental disorder to patients who have the capacity to refuse at some times, or all of the time, is possible under the procedures of the Mental Health Act 1983.

[58] Paragraph 15.15.

[59] *Re W* [1992] 3 W.L.R. 758, 769.

[60] Paragraphs 3.27-3.35.

to medical decision-making and, in particular, whether the idea that an apparent consent might not represent a "true choice" might cause any difficulties for those treating mentally disordered patients.

2.20 We do not consider that a person should be considered incapacitated unless the absence of an independent will has been caused by a mental disorder.[61] The adoption of this proposal will not, therefore, constitute an exception to the requirement that a mental disorder must be present. We provisionally propose that:

> **3. A mentally disordered person should be considered unable to take the medical treatment decision in question if he or she can understand the information relevant to taking the decision but is unable because of mental disorder to make a true choice in relation to it.**

Inability to communicate

2.21 We included an inability to communicate a decision in the definition of incapacity proposed in Consultation Paper No.128.[62] In *Re F*, Lord Bridge and Lord Goff both said that at common law those who are unable to communicate should be included among those who are unable to consent to treatment.[63] We consider that such people should also be regarded as incapacitated for the purposes of a statutory scheme relating to medical decision-making. Those who are unable both to make a decision and to communicate it (for example, because they are unconscious) and those who can understand enough to make a decision but cannot communicate it to others (for example, because of a stroke) should all be treated as incapacitated for the purposes of the scheme. In some cases it will not be possible to tell whether a person who lacks the

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[61] The Mental Health Act Commission's opinion is that anorexia nervosa falls within the definition of mental disorder in the Mental Health Act 1983, *Fourth Biennial Report 1989-1991* (1991), para. 6.18.

[62] Paragraph 3.41.

[63] [1990] 2 A.C. 1, 75 *per* Lord Goff; 52 *per* Lord Bridge.

capacity to communicate also lacks the capacity to understand.[64] Every effort should of course be made to find ways of communicating with such a person, and a person who is unable to communicate should not be assumed to be unable to understand. Nevertheless, we do not believe that there would be any advantage in reforming the law in one situation but not the other. Suggestions would be welcome as to whether in any of our other proposals we ought to distinguish between different situations which may give rise to incapacity. As in Consultation Paper No.128, we consider that the requirement to establish mental disorder should not apply to those who are unable to communicate a decision. We provisionally propose that:

> **4. A person, whether or not suffering from mental disorder, should be considered unable to take the medical treatment decision in question if he or she is unable to communicate it to others who have made reasonable attempts to understand it.**

The relevant age

2.22 Although this project is concerned with incapacitated adults, in Consultation Paper No.128 we proposed to include those aged 16 or 17 who meet the test of incapacity. This also has attractions in relation to medical treatment. The effect of section 8 of the Family Law Reform Act is to treat 16 year olds as adults in some respects for the purposes of giving consent to medical treatment.[65] A number of the

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[64] The Medical Ethics Committee of the BMA refers, in a Discussion Paper published in September 1992, to "locked in syndrome", a condition in which paralysis rather than cognitive failure prevents communication and awareness may be fully or partially preserved (*Discussion Paper on Treatment of Patients in Persistent Vegetative State*, p.5). A recent New Zealand case concerned a patient with Guillain-Barré syndrome. This affected the nervous system so that the brain was said to be entirely disengaged from the body. Sensory deprivation was thought to have left the brain in a drowsy semi-working state (*Auckland Area Health Board* v. *Attorney-General* [1993] 1 N.Z.L.R. 235). The patient in the Canadian case, *Re Eve*, was learning disabled and also suffered from extreme expressive aphasia which rendered her unable to communicate her thoughts ((1986) 31 D.L.R. (4th) 1).

[65] Section 8(1) provides that the consent of a minor who has attained the age of sixteen years to any treatment which, in the absence of consent, would constitute a trespass to his person, shall be as effective as if he were of full age. But see the interpretation of this section by the Court of Appeal in *Re W* [1992] 3 W.L.R. 758. See also s.131 of the Mental Health Act 1983, which applies to a minor who has attained the age of 16 years and is "capable of expressing his own

cases which have reached the courts under the existing law have been concerned with young women with learning disabilities and there may be no significant differences between the situations of those who have reached 18 and those who have not. The age of 16 might be a more appropriate boundary for the exercise of a jurisdiction to make medical treatment decisions on behalf of incapacitated patients.

2.23 However, we do not propose restricting the inherent jurisdiction of the High Court or the statutory jurisdiction under the Children Act 1989, both of which extend up to a person's eighteenth birthday. It appears that a child might be regarded as incapacitated by courts exercising either of those jurisdictions, but capable on the test we have proposed.[66] The parental responsibility to consent on behalf of an incapacitated child[67] would also continue until majority. Nevertheless, there are likely to be cases where it would be appropriate to have recourse to the new jurisdiction, for example, so that arrangements can be made which will continue in effect after an incapacitated child becomes an adult. We provisionally propose that:

5. The new jurisdiction should extend to persons aged 16 and over.

Summary

2.24 In summary we provisionally propose that any new jurisdiction to approve medical treatment on behalf of an incapacitated person should be available in respect of people of or over the age of 16 who are:

(1) suffering from mental disorder within the meaning of the Mental Health Act 1983 and unable to understand an explanation in broad terms and simple language of the basic information relevant to

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wishes", s.131(2).

[66] See *Re R* [1992] Fam. 11, 26, discussed at para. 2.17 above.

[67] It appears that a parent may also be able to consent to the treatment of a capable child (see *Re W* [1992] 3 W.L.R. 758). Decisions relating to such a child could not be made within the jurisdiction outlined in this paper.

taking the decision in question, including information about the reasonably foreseeable consequences of taking or not taking it, or unable to retain that information for long enough to take an effective decision; or

(2) unable by reason of mental disorder within the meaning of the Mental Health Act 1983 to make a true choice in relation to the decision in question; or

(3) unable to communicate the decision in question to others who have made reasonable efforts to understand it.

PART III

THE TREATMENT OF THE INCAPACITATED PATIENT

The patient's "anticipatory decisions"

3.1 Once a doctor has concluded that a patient is not capable of providing consent to a proposed medical treatment, some legal justification is required before treatment may be given without consent. Often it will be necessary to make a decision for the incapable person, but it may be that the patient has previously decided which treatment he would or would not be prepared to accept in these circumstances.

The present law

3.2 Lord Keith has said that the complete liberty of the patient who is conscious and of sound mind to decline to undergo treatment, even where death will be the result, extends to the situation where such a person, in anticipation of his incapacity, gives clear instructions that in such event he is not to be given medical care, including artificial feeding, designed to keep him alive.[1] Lord Goff has said that the same principle of self-determination which permits a patient of sound mind to require that life support should be discontinued applies where the patient's refusal to give his consent has been expressed at an earlier date, before he became unconscious or otherwise incapable of communicating it. However, he added that in such circumstances especial care may be necessary to ensure that the prior refusal of consent is still properly to be regarded as applicable in the circumstances which have subsequently occurred.[2]

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[1] *Airedale NHS Trust* v. *Bland* [1993] 2 W.L.R. 316, 360-361.

[2] *Ibid.*, at p.367.

3.3 The ability of a patient to make an anticipatory choice which can bind a treatment provider was considered in some detail by the Court of Appeal in *Re T.*[3] Lord Donaldson M.R. said that if, at the time when the decision was made, a patient had the capacity to decide and exercised his right to do so, doctors must not conclude that if the patient had still possessed the necessary capacity in the changed situation he would have reversed his decision. He said that this "would be simply to deny his right of decision".[4] For an example of a decision which would have continued to be binding, all three members of the Court of Appeal cited the Canadian case of *Malette* v. *Shulman*,[5] which involved a Jehovah's Witness who carried a card stating that she did not wish to have blood administered in any circumstances. Butler-Sloss L.J. said that doctors who treat such a patient against his known wishes do so "at their peril".[6]

3.4 Lord Donaldson M.R. said that in some cases it will not be of great importance to the patient's health whether he is treated immediately, or perhaps at all. In other cases the patient may choose one treatment, which the doctor is prepared to undertake, rather than another, which the doctor considers preferable. But, he said, where an adult patient declines to consent to treatment which is necessary to prevent loss of life or irreparable damage to health, there are two conflicting interests. The patient's interest consists of his right to self determination, his right to live his own life how he wishes even if it will damage his health or lead to his premature death. In contrast to this, there is a very strong public interest in preserving the life and health of all citizens and in upholding the concept that all human life is sacred and that it should be preserved if at all possible. Lord Donaldson said that ultimately the individual's right to self-determination is paramount, but where there is doubt over whether, or in which way, the individual is exercising that right, that doubt falls to be resolved in favour of the

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[3] [1992] 3 W.L.R. 782.

[4] *Ibid.*, at p.797.

[5] (1990) 67 D.L.R. (4th) 321.

[6] [1992] 3 W.L.R. 782, 800.

preservation of life.[7] An anticipatory decision will be binding on doctors if it is "clearly established" and "applicable in the circumstances"; and, Lord Donaldson said, these are two major "ifs".[8]

3.5 Lord Donaldson said that doctors faced with an anticipatory decision will have to consider the true scope and basis of the decision and whether at the time it was made it was intended by the patient to apply in the changed situation. A refusal is only effective within its true scope and will be vitiated if based upon false assumptions. In *Malette* v. *Shulman*, blood was not to be administered under *any* circumstances, but some refusals may be more limited in scope, perhaps applying "so long as there is an effective alternative".[9] In *Malette* v. *Shulman*, it was clear that the patient was aware of the serious or fatal consequences of her decision but in *Re T* the patient may have been led to believe that there were effective alternatives or that the need for treatment would not arise.[10] Lord Donaldson said that when a patient, with a full appreciation of the possible consequences, makes a declaration of his decision to refuse to accept blood transfusion, on a hospital's standard form, then the possible consequences should be expressed in the simplest possible terms and emphasised.[11]

3.6 In *Malette* v. *Shulman*, the Ontario Court of Appeal made it clear that it was not concerned with "a patient who has been diagnosed as terminally or incurably ill who seeks by way of advance directive or 'living will' to reject medical treatment so that she may die with dignity".[12] However, in a later case the same court referred to the right to give binding advance directives as a "traditional common law principle".

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[7] *Ibid.* at pp.795-796. The interests of the individual may also outweigh the principle that human life should be preserved if at all possible when treatment which prolongs the patient's life is not in the patient's best interests. See *Re J* [1991] Fam. 33, 52 *per* Balcombe L.J.; *Airedale NHS Trust* v. *Bland* [1993] 2 W.L.R. 316, 371 *per* Lord Goff.

[8] [1992] 3 W.L.R. 782, 787.

[9] *Ibid.*, at pp.797-799.

[10] *Ibid.*, at p.803.

[11] *Ibid.*, at p.798.

[12] (1990) 67 D.L.R. (4th) 321, 332.

"A patient, in anticipation of circumstances wherein he or she may be unconscious or otherwise incapacitated and thus unable to contemporaneously express his or her wishes about a particular form of medical treatment may specify in advance his or her refusal to consent to the proposed treatment. A doctor is not free to disregard such advance instructions, even in an emergency. The patient's right to forego treatment, in the absence of some overriding societal interest, is paramount to the doctor's obligation to provide medical care. This right must be honoured, even though the treatment may be beneficial or necessary to preserve the patient's life or health, and regardless of how ill-advised the patient's decision may appear to others."[13]

3.7 In England and Wales, the dicta in *Re T*, together with those in *Airedale NHS Trust* v. *Bland* in both the Court of Appeal[14] and the House of Lords[15] indicate that an anticipatory decision which is "clearly established" and "applicable in the circumstances" may be as effective as the current decision of a capable adult.

Advance directives

3.8 It was suggested in *Re T* that contact with the patient's "next of kin" may reveal that the patient has made an anticipatory choice.[16] However, where there is no written evidence of this, the patient's decision may not be "clearly established".[17] For this reason a patient may be well advised to prepare a written document which sets out

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[13] *Fleming* v. *Reid* (1991) 82 D.L.R. (4th) 298, 310.

[14] Sir Thomas Bingham M.R. referred to the "important principle" that a medical practitioner must comply with clear instructions given by an adult "of sound mind" as to the treatment to be given or not to be given in certain circumstances, even if by the time the circumstances obtain, the patient is unconscious or no longer of sound mind, [1993] 2 W.L.R. 316, 334. Butler-Sloss L.J., at p.342, noted the agreement of counsel that the right to reject treatment extends to deciding not to accept treatment in the future by way of advance directive or "living will".

[15] See para. 3.2 above.

[16] [1992] 3 W.L.R. 782, 787.

[17] See A. Grubb, [1993] 1 Med.L.Rev. 84, p.87.

clearly any decisions he wishes to make. The possibility of "advance directives",[18] including "living wills",[19] was discussed in Consultation Paper No.119.[20] Many respondents supported this concept. However, a number expressed concern at or opposition to the use of advance directives for the purpose of refusing life-sustaining treatment.[21]

3.9 A BMA statement, published in May 1992, strongly supported the principle of advance directives. Their value was seen to lie in providing an opportunity for patients to open a dialogue with their doctors about their future care, in providing a means for patients to exercise their autonomy, and in offering relief to relatives when patients have made their own treatment decisions in advance of incapacity. The BMA perceived a significant difference between euthanasia, on the one hand, and this way of exercising the patient's right to accept or reject treatment options on the other.[22] Lord Goff has said that there would be no question of a patient who declines treatment in this way having committed suicide.[23]

3.10 A recent study of the attitudes of patients, nurses and doctors working in the field of HIV and AIDS suggested similar benefits. However, the author argued that there could be substantial disadvantages to detailed legislation on advance directives,

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[18] We use the term "advance directive" for a document which is intended to demonstrate that a patient has made an anticipatory decision, and the scope of the decision made.

[19] The term "living will" typically refers to an advance directive which is concerned with the refusal of life-sustaining procedures in the event of a terminal illness. However, the term is sometimes used for advance directives which are concerned with other situations or which can be used to express a willingness to receive particular treatments. See, for example, the "Living Will" form developed by the Terrence Higgins Trust and the Centre of Medical Law and Ethics, King's College London. This is discussed at para. 3.15 below.

[20] Paragraphs 6.2-6.9.

[21] See, for example, the article based on the responses to the Consultation Paper of the Edmund Plowden Trust and the Bio-Ethics Group of the Newman Association: M. Brown, R. Ombres and A. Cole, "Mentally Incapacitated Adults and Decision-Making", (1992) 112/113 Law & Justice 23, p.30.

[22] *Statement on Advance Directives* (1992), pp.1-2.

[23] *Airedale NHS Trust* v. *Bland* [1993] 2 W.L.R. 316, 367.

and that the publication of guidelines might be a better option in this area of practice.[24] The BMA has also argued that "mutual respect and common accord is better achieved without legislation".[25] We see the force of these views. However, legislation in this area would resolve the uncertainty of the law as it stands, which leaves both doctors and patients unclear about their respective positions. The BMA took the view that advance directives did not have legal force,[26] but doubts and concerns regarding the legal status of living wills have certainly been reported.[27] Following the dicta of the House of Lords in *Airedale NHS Trust* v. *Bland* it appears that it may be possible to make an advance directive which is legally binding. Concern both about what is needed to achieve such an effect and about the consequences such documents might have is likely to increase.

3.11 If a statutory framework for decision-making for incapacitated adults of the sort proposed in this paper were introduced, it would be difficult to avoid consideration of the extent to which courts and other decision-makers, including doctors, should be bound by relevant decisions made by a patient prior to his incapacity. Legislation could clarify the position and could also provide solutions to a range of ancillary matters. For example, although the BMA argued that a doctor is not bound to comply with an anticipatory decision, it also suggested that if he does comply he could not be found to have been negligent in so doing.[28] Legislation could also make it clear that a doctor who acts in good faith and with reasonable care, in accordance with an advance directive which he believes to be valid, should not be exposed to liability even if the directive is subsequently shown to be invalid.[29] Limitations on the scope of

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[24] C. Schlyter, *Advance Directives and AIDS* (1992), pp.68-69 (Centre of Medical Law and Ethics).

[25] *Statement on Advance Directives* (1992), p.4.

[26] *Ibid.*, p.3.

[27] See, for example, C. Schlyter, *Advance Directives and AIDS* (1992), p.56.

[28] *Statement on Advance Directives* (1992), p.8.

[29] See para. 3.35 below.

anticipatory decision-making might also be appropriate.[30] Another role for legislation would be to introduce penalties for the wrongful concealment, alteration, falsification or forgery of an advance directive.[31] Finally, in the Ontario case of *Fleming* v. *Reid*, it was recognised that the resolution of questions about the clarity or currency of a patient's wishes, their applicability to present circumstances, and whether they have been revised or revoked were all matters for legislation.[32] Therefore we provisionally propose that:

1. Legislation should provide for the scope and legal effect of anticipatory decisions.

3.12 The BMA recommended strongly that advance directives should not be legally binding.[33] It argued that patients might request treatments which are clinically inappropriate, or which distort resource allocation, or which are illegal, such as active euthanasia. However, as the BMA's own statement says, patients cannot insist on the provision of treatments which clinical expertise indicates to be futile for their condition or which diverts resources from other patients,[34] and requests for euthanasia are also legally ineffective. A legally "binding" advance directive does not enable the patient to make demands which he could not lawfully have made when capable. However, the BMA's main concern was that patients might inadvertently misdirect doctors by an

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[30] See paras. 3.22-3.31 below.

[31] See para. 3.36 below.

[32] (1991) 82 D.L.R. (4th) 298, 318. See paras. 3.13-3.21, 3.32-3.34, 4.15-4.17 below. In Ontario, the Consent to Treatment Act 1992 has now been passed which includes provisions relating to anticipatory decision-making. Proposals for legislation have been made in a number of other Canadian provinces: Manitoba Law Reform Commission, Self-Determination in Health Care (Living Wills and Health Care Proxies) (1991), Report No.74; Alberta Law Reform Institute, Advance Directives and Substitute Decision-Making in Personal Health Care (1991), Report for Discussion No.11; Newfoundland Law Reform Commission, Discussion Paper on Advance Health Care Directives and Attorneys for Health Care (1992), NLRC - WP6; Saskatchewan Law Reform Commission, Proposals for an Advance Health Care Directive (1992).

[33] *Statement on Advance Directives* (1992), p.4.

[34] *Ibid.*, p.10.

inadequate appreciation of the circumstances or the evolution of new treatments.[35] This concern was shared by some respondents to Consultation Paper No.119 and one possibility would be for legislation to state that anyone providing medical treatment to an incapacitated patient is not bound by any anticipatory decisions which the patient may have made.

3.13 On the other hand, it might be possible to address the anxieties which surround advance directives without depriving anticipatory decisions which are "clearly established" and "applicable in the circumstances"[36] of the force which they probably already have under the common law. The BMA was concerned about the patient who is inadequately informed, but it appears to us that directives given in such circumstances would not be "applicable" in the circumstances about which the patient had not been adequately informed. A decision which is based upon false assumptions would be vitiated.[37] The BMA was also concerned that some patients may informally indicate a change of view from that recorded in an advance directive.[38] However, we consider that, as was said in *Malette* v. *Shulman*,[39] a doctor would be entitled to proceed with treatment if there was evidence which cast doubt on whether a directive was a true expression of the patient's wishes.[40] Legislation recognising the patient's "right of decision"[41] might be acceptable if it also provided a mechanism to which cases could be referred where there was doubt about the validity or applicability of the patient's decision.[42] Legislation might also give protection from liability to a treatment provider

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[35] *Ibid.*, p.4.

[36] The two requirements which Lord Donaldson M.R. said must be satisfied, *Re T* [1992] 3 W.L.R. 782, 787.

[37] *Ibid.*, at p.799 *per* Lord Donaldson M.R.

[38] *Statement on Advance Directives* (1992), p.4.

[39] (1990) 67 D.L.R. (4th) 321, 335-336

[40] Oral revocation of advance directives is considered at para. 3.33 below.

[41] *Re T* [1992] 3 W.L.R. 782, 797 *per* Lord Donaldson M.R.

[42] See paras. 3.28 and 4.15-4.17 below.

who acted reasonably.[43] As a starting point, and in accordance with what appears to be the common law position, we provisionally propose that:

> 2. **If a patient is incapacitated, and subject to the other proposals in Part III of this paper, a clearly established anticipatory decision should be as effective as the contemporaneous decision of the patient would be in the circumstances to which it is applicable.**

The form of anticipatory decisions

3.14 If statutory clarification of anticipatory decision-making is considered desirable it would be possible to develop a prescribed form with specified consequences. A working party which considered living wills in 1988 regarded the use of a prescribed form as desirable, since patients might otherwise find it difficult to express their own views unambiguously, or might make requests which were medically unsound or legally untenable.[44] It has also been suggested that doctors might find it difficult to adopt a workable practice if they kept encountering a range of different documents.[45]

3.15 On the other hand, if no prescribed form were introduced, different forms of advance directive could be developed to cater for the concerns of different patients. This approach is demonstrated by the living will developed by the Terrence Higgins Trust and the Centre of Medical Law and Ethics ("the THT Living Will"), which was launched in September 1992. This was specifically designed for people with HIV and AIDS, after extensive consultation with people concerned, service organisations and doctors involved in the area. Its provisions could be adapted to other situations, after similar consultation. Equally, a more general form could be produced as a model, but

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[43] See paras. 3.35 and 3.71-3.72 below.

[44] Age Concern Institute of Gerontology and the Centre of Medical Law and Ethics, *The Living Will: Consent to treatment at the end of life* (1988), p.54.

[45] C. Schlyter, *Advance Directives and AIDS* (1992), p.70.

its use would not be mandatory.[46] This could be done by the Law Commission after appropriate consultation, but we see significant advantages in a more broadly based group undertaking this work. We invite comment on whether a model form should be developed and, if so, by whom.

3.16 In circumstances in which an anticipatory decision would be binding at common law, we would be reluctant to deprive it of validity merely because it is not made in a particular form. The decision of the Court of Appeal in *Re T* suggests that an anticipatory decision may take a variety of forms, including a hospital's standard form of refusal, a "no blood" card carried by a Jehovah's Witness or a spoken refusal repeated to the patient's doctor, nurse and midwife, in the presence of family members.[47] The BMA suggested that oral remarks which might be made impulsively or when a patient is despondent are unlikely to be indicative of a considered view or stable opinion, and should be in a different category from written advance directives.[48] We agree that an impulsive remark should not be regarded as an anticipatory decision. It would not be "clearly established" nor would it be "applicable to" circumstances outside the patient's contemplation, but other decisions expressed orally might be both. We invite views on the practical implications of oral anticipatory decision-making.

3.17 Although a flexible approach to the form of anticipatory decisions may be necessary, we consider that patients should be encouraged to make their views known in a more formal way. One approach, adopted recently by the Manitoba Law Reform Commission, is to provide for "health care directives" in a statutory scheme, coexisting with the common law. By this means, any directive not made in the prescribed manner

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[46] In the law reform proposals referred to above, n.32, a model form was favoured by the Newfoundland LRC and the Manitoba LRC, but not by the Saskatchewan LRC or the Alberta LRI.

[47] Ward J. considered that such expressions could be binding, *Re T* [1992] 3 W.L.R. 792. The Court of Appeal did not discuss the issue, but Lord Donaldson M.R. said, at p.795, that it would be unfortunate if Ward J.'s findings of fact were regarded as giving any indication of how other cases should be approached.

[48] *Statement on Advance Directives* (1992), p.5.

would not be prevented from taking effect in accordance with common law principles.[49] In the Manitoba proposals, a decision will be recognised as effective by statute provided that it is made in writing and signed, but an oral direction given immediately before surgery is suggested as an example of a direction which would almost certainly continue to be valid at common law.[50] However, if the effect of informal decisions was left entirely to the common law, this might lead to unnecessary uncertainty and could undermine any restrictions which legislation attempted to impose upon the scope of anticipatory decision-making.[51] For the purposes of any new scheme, we propose that there should be a rebuttable presumption that an anticipatory decision is "clearly established" until it is revoked, provided that it meets certain statutory requirements. The presumption would not affect questions about the applicability or relevance of the decision. We invite views on whether there should also be a rebuttable presumption that a decision is not "clearly established" if it is made in a form which does not meet the statutory requirements.

3.18 We envisage that several copies of such a form might be in use. These might be lodged with the patient's General Practitioner, family members or friends. All the copies might be individually signed and witnessed, but photocopies might also be made. In many cases, we consider that a photocopy would be sufficient to establish the existence of an anticipatory decision. We do not consider that an apparent decision should be disregarded simply because the original document is not immediately available. However, if there is any doubt about the validity of the document, the original should be sought. Alternatively there could be an authentication procedure.[52] We invite comment on how copies of a document should be treated.

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[49] Manitoba LRC, Report No.74, p.11. The same approach is proposed in Newfoundland LRC, WP6, p.95.

[50] Manitoba LRC, Report No.74, p.26.

[51] See paras. 3.22-3.31 below.

[52] At para. 3.42 below, we suggest that essential treatment might be provided in an emergency while the validity of a doubtful refusal is established by a judicial forum.

3.19 Strict formal requirements reduce accessibility, and would increase the number of decisions whose status would be uncertain, because it would not be clear whether or not they were "clearly established". However, formalities of execution can serve to minimise undue influence and fraud, provide reliable and permanent evidence of the maker's intentions, and impress the significant consequences of a decision upon the maker.[53] We believe that witnessing is an important safeguard which should be encouraged. An unwitnessed document might still constitute a valid anticipatory decision, especially if a card of some kind is carried as a verification of the patient's "continuing and current resolve" as in *Malette* v. *Shulman*.[54] However, we consider that there should be no presumption in favour of an unwitnessed document. The proposals in Alberta and Newfoundland require one witness, on the basis that to require two would not be a significantly more effective safeguard.[55] We invite comment on the number of witnesses, if any, and on their qualifications. We propose that a person who is the patient's "medical treatment attorney"[56] should not be able to act as a witness and we invite comment on whether the spouse of such an attorney should also be excluded.[57] Other possible restrictions might exclude the maker's close relatives or those with an interest in his estate,[58] or those expected to provide the medical treatment in question. We provisionally propose that:

> **3. There should be a rebuttable presumption that an anticipatory decision is clearly established if it is in writing, signed by the maker [with appropriate provision for signing at his direction], and witnessed by [one] person who is not the maker's medical treatment attorney.**

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[53] See Manitoba LRC, Report No.74, p.12, proposing that witnessing of a signed written directive should not be required.

[54] (1990) 67 D.L.R. (4th) 321, 337. The BMA suggested that patients should carry cards indicating the location of an advance directive, as well as lodging copies with their doctor.

[55] Alberta LRI, Report for Discussion No.11, p.50; Newfoundland LRC, WP6, p.65.

[56] For discussion of medical treatment attorneys see Part V below.

[57] This restriction is included in the Alberta LRI and Newfoundland LRC proposals.

[58] Both are regarded as unsuitable in the THT Living Will.

3.20 We do not favour a requirement that a witness must be a doctor or solicitor who would certify that the maker had capacity to make the decision. Nevertheless, one of the benefits of advance directives is that a patient can talk the matters involved over with his doctor prior to any incapacity. The BMA very strongly recommended that patients who wish to draft advance directives should do so with medical advice, and that they should be told of the risks as well as the benefits of making such a document.[59] Doctors should share with the patient information about diagnoses, prognoses and realistic treatment options and listen to the patient's views.[60] In addition to helping the doctor overcome any doubt that the person is capable at the time the directive is prepared and signed, such a discussion would give the doctor the opportunity to tell his patient if he objects in principle to the advance directive. This would enable the patient to consult another practitioner, or reconsider his decisions.[61] It has been suggested that the need for the patient to anticipate the eventual medical condition to which his decision may have to apply makes it more likely that an anticipatory decision will be found valid if it is arrived at in consultation with a doctor, and drawn up at a time when the patient and his doctor have the patient's prognosis and treatment options in mind.[62]

3.21 However, where an unanticipated situation occurs the patient's general intention may be frustrated, unless he can nominate a "proxy" who would apply the patient's wishes to the particular situation.[63] The BMA considered that, where treatment options cannot be predicted, a simple statement of the patient's views may be more helpful than a complicated document which tries to cover all possibilities,[64] and that a system of "proxies" could meet new circumstances as they arise, reflecting the patient's true

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[59] *Statement on Advance Directives* (1992), p.3.

[60] *Ibid.*, p.5.

[61] *Ibid.*, pp.7-8.

[62] A. Grubb, [1993] 1 Med.L.Rev. 84, p.87.

[63] *Ibid.*, p.87.

[64] *Statement on Advance Directives* (1992), p.7.

wishes, rather than being tied to the particular words of an advance directive.[65] In other parts of this paper we consider the appointment of substitute decision-makers either by the person concerned while capable,[66] or by someone on his behalf.[67] Patients should certainly be able to record information and views to guide those making decisions for them as well as, or instead of, making anticipatory decisions.

The limits on anticipatory decision-making

3.22 Legislation in the United States[68] and in Australia[69] has been concerned solely with the use of advance directives to refuse treatment in cases of "terminal illness". This limitation may overlook the needs of many other patients who wish to exercise control over their medical treatment after they become incapacitated, such as those involved in accidents, and those who wish to express a consent rather than a refusal, or to choose one treatment rather than another.[70] The Saskatchewan Law Reform Commission has proposed legislation which applies only to advance directives taking effect in a "last illness",[71] but it has been proposed in a number of other Canadian states that patients should be enabled to give directions about all health care decisions taken on their behalf.[72] We agree with the latter approach. No doubt, many decisions will be made to be applicable at the end of life,[73] but we consider that anticipatory

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[65] *Ibid.*, p.3.

[66] See Part V below. The term "medical treatment attorney" is used for a substitute decision-maker appointed by the patient in advance of incapacity.

[67] See paras. 4.20-4.29 below. The term "proxy" is reserved for this situation.

[68] For example, the California Natural Death Act 1976.

[69] The South Australia Natural Death Act 1983 and the Northern Territory Natural Death Act 1988.

[70] Manitoba LRC, Report No.74, p.4.

[71] Saskatchewan LRC, Proposals for an Advance Health Care Directive (1992), p.29.

[72] Alberta LRI, Report for Discussion No.11, p.47; Newfoundland LRC, WP6, p.46; Manitoba LRC, Report No.74, p.6.

[73] See for example the THT Living Will, Case 1 - "I have a physical illness from which there is no likelihood of recovery, *and* it is so serious that my life is nearing its end".

decision-making should be possible in any situation where the patient may be incapable of making his own decisions.

3.23 For the same reason, we propose that the scope of anticipatory decisions should not be confined to those who are permanently incapacitated.[74] If it is possible to delay a decision until the patient is able to decide for himself then this should be done, but the patient should be able to exercise control over all the decisions made on his behalf while he is incapable, whether his incapacity is permanent or temporary.

3.24 We recognise that such an approach will generate its own problems. The BMA suggested that an advance directive refusing treatment which is futile, or which most people would reject, will often coincide with good medical practice, but that a mechanism should be available where the directive conflicts with widespread medical opinion.[75] A capable adult patient has an absolute right[76] to refuse medical treatment for reasons which are rational, irrational, unknown or non-existent, and it is possible that the common law right to make anticipatory decisions is just as broad. However, there may be a case for placing some limitations on the scope and effectiveness of such decisions, given that the patient will suffer the consequences only after it is too late for him to change his own mind.

3.25 The first possible limitation relates to the type of treatment which may be refused in such a document. Andrew Grubb has suggested that it would be contrary to public policy to require a doctor to "abandon" a patient who has refused "basic care", such as nursing care.[77] Similar considerations may apply to prevent an incapacitated patient being left in great pain because of an earlier refusal of palliative care. In its

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[74] As suggested in *The Living Will* (1988), p.52.

[75] *Statement on Advance Directives* (1992), p.5.

[76] The possible, and very controversial, exception to this right, where a viable foetus is endangered (see para. 2.1, n.4 above) is considered at para. 3.31 below.

[77] A. Grubb, [1993] 1 Med.L.Rev. 84, p.85. He suggests that a public policy prohibition on the refusal of nursing care may be based upon the interests of professionals and other patients who would be affected by the refusal. On this basis, the prohibition might extend to capable patients.

paper, the BMA recommends that such medical care and pain relief should be given as would appear "acceptable to the patient and appropriate to the circumstances".[78] We consider that the acceptability of "basic care" and pain relief should be judged according to the patient's current needs and wishes (if his wishes can be discerned) without reference to his prior instructions. We would not expect many people to wish to make a directive refusing basic care or pain relief and we do not regard this as a significant infringement of the patient's rights of self determination. We invite comment on the content of the category of "basic care".

3.26 Although some American legislation excludes nutrition and hydration from the category of treatments which can be refused,[79] the BMA considered it should be possible to refuse artificial feeding in an advance directive.[80] We share this view. Artificial feeding is a form of treatment which a patient should be entitled to refuse in an advance directive, and if such a directive is discovered after artificial feeding has been started it should be withdrawn.[81] It should also be withdrawn if the circumstances to which the directive applies, such as persistent vegetative state, can only be reliably diagnosed after some time. It has been accepted by the House of Lords that artificial feeding can lawfully be withdrawn and Lord Keith referred explicitly to a person giving instructions that in certain circumstances he is not to be given medical care, including artificial feeding, designed to keep him alive.[82] We would, however, see spoon-feeding as coming within the category of "basic care".[83] We provisionally propose that:

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[78] *Statement on Advance Directives* (1992), p.10.

[79] A list of legislation which excludes nutrition and hydration is contained in I. Kennedy and A. Grubb, *Medical Law: Text and Materials* (1989), p.1133.

[80] BMA, *Statement on Advance Directives* (1992), p.9.

[81] *Ibid.*, p.9.

[82] *Airedale NHS Trust* v. *Bland* [1993] 2 W.L.R. 316, 360-361.

[83] See BMA Medical Ethics Committee, *Discussion Paper on Treatment of Patients in Persistent Vegetative State* (1992), p.21, which suggests that different methods of nutrition can be distinguished. Feeding by gastrostomy or nasogastric tube can be withdrawn on the same grounds as those upon which doctors discontinue other treatments, but "care" must continue beyond the withdrawal of specific treatments.

4. An anticipatory decision should be regarded as ineffective to the extent that it purports to refuse pain relief or "basic care", including nursing care and spoon-feeding.

3.27 Another possible limitation relates to the circumstances in which treatment might be refused. A capable individual may fail to appreciate the value which he might place on his life in a situation he imagines he would find intolerable when thinking about it in advance.[84] For example, an advance directive might refuse all life-sustaining treatment, including anti-biotics, if the maker suffers a serious loss of cognitive function. In the event, the maker of the directive suffers a discrete neurological injury which renders him incapable of understanding information relevant to even the most simple treatments, but he is otherwise healthy and apparently quite happy. If he then develops a life-threatening pneumonia and his doctors follow the instructions given in the directive, the result will be the easily avoidable death of a happy and healthy individual.[85] It is difficult to formulate an appropriate restriction to deal with cases such as this. One approach might be to provide that an anticipatory decision is ineffective if the incapacitated patient "objects".[86] Safeguards are certainly required for such a patient,[87] but the incapacitated patient who acquiesces to anything which is done (or not done) may also require protection. The situation described in this paragraph is just one example of the difficult cases which will inevitably arise, whether or not legislation is introduced. We consider that the most appropriate response would be to provide a forum to which the most troubling cases could be referred.

3.28 In cases of doubt or dispute, a judicial forum should be available to determine whether an anticipatory decision is "clearly established" and "applicable to the

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[84] C. Schlyter, *Advance Directives and AIDS* (1992), p.35.

[85] The example is from A. Buchanan and D. Brock, *Deciding for Others* (1989), pp.108-109. In the THT Living Will the patient may state that if he becomes permanently mental impaired he does not wish to be kept alive by medical treatment, but only if the impairment is so severe that he does not understand what is happening to him.

[86] Based on the Californian Durable Power of Attorney for Health Care Act 1983. See *The Living Will* (1988), p.73.

[87] See paras. 3.44-3.45 and 4.31-4.32 below.

circumstances". In *Re T*, Ward J. was able, in the circumstances of that case, to construe an apparently unequivocal refusal of treatment as not extending to the extreme situation which subsequently arose.[88] Lord Donaldson M.R. said that a decision may be intended to apply "so long as there is an effective alternative" to a particular treatment.[89] In the example of the healthy and happy incapacitated person,[90] there might be evidence that the decision was intended to apply where the incapacity occurred in the course of a terminal illness involving distress and pain. The possibility of being incapacitated but healthy and happy, might not have been considered. We recognise the danger that the approach suggested in this paragraph might threaten the patient's right of self-determination if the category of situations to which the decision applies is restricted too much. A genuine attempt to identify the true intentions of the maker is essential. This might be assisted by consultation with the patient's relatives[91] or medical treatment attorney if one has been appointed,[92] or by discussions between the treatment provider and the patient in advance.

3.29 It would also be possible to give a judicial forum the power to override an anticipatory decision even if it was "clearly established" and "applicable in the circumstances". This could either be a general power or could be limited to particular circumstances. For example, there might be a presumption that an anticipatory decision should be respected, but treatment could be authorised when the decision is found to be clearly contrary to the patient's best interests. We are not at present persuaded that there is any need for a power to override, as opposed to a power to determine the scope and validity of, a patient's anticipatory decision, but we invite views on this.

3.30 Legislation which has dealt with this question in other countries has limited the jurisdiction to override anticipatory decisions to specific categories of case. For

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[88] [1992] 3 W.L.R. 782, 798.

[89] *Ibid.*, at p.798.

[90] See para. 3.27 above.

[91] See paras. 3.59-3.67 below.

[92] See Part V below.

example, recent legislation in Ontario provides that a person's "wishes"[93] may be overridden if the Consent and Capacity Review Board is satisfied that the incapable person would probably, if capable, give consent because the likely result of the treatment is significantly better than would have been anticipated in comparable circumstances at the time the decision was made.[94] The Newfoundland Law Reform Commission, on the other hand, considered that it was unnecessary to provide any such explicit mechanism, since the duty to interpret the patient's instructions left enough scope for such considerations to be taken into account.[95] For the same reason we do not propose any specific provision to cover those cases in which there have been advances in treatment which were not anticipated at the time the anticipatory decision was made.

3.31 Another situation in which it has been suggested that an anticipatory decision could be overridden is where a woman refuses life-sustaining treatment during the course of a pregnancy.[96] The BMA has argued that the requests of the woman have to be weighed against a moral duty to another human being[97] and the Scottish Law Commission has argued that a terminally ill woman ought to be kept alive for "longer than strictly necessary" if there is a reasonable chance of thereby saving her unborn child.[98] There are dicta which could be construed as suggesting that a capable patient's current refusal may be overridden if a viable foetus is endangered.[99] However, this is a highly controversial and difficult question which it is not necessary for us to explore here. Whatever the position in relation to a capable patient, we do not think that any

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[93] A person may, while capable, express wishes with respect to treatment in a power of attorney, in a prescribed form, in another written form, orally or in any other manner, Consent to Treatment Act 1992, s.12.

[94] *Ibid.*, s.31(3).

[95] Newfoundland LRC, WP6, p.85.

[96] See, for example, *The Living Will* (1988), p.60.

[97] *Statement on Advance Directives* (1992), p.10.

[98] Scottish Law Commission Discussion Paper No.94, paras. 5.111.

[99] See para. 2.1, n.4, above.

greater restriction should be imposed upon any anticipatory decision of a pregnant woman.

Revocation

3.32 It will only be relevant to consider the terms of an anticipatory decision if its maker is incapable of taking the decision to which it relates. However, it is possible that a patient will have sufficient understanding to revoke an advance directive although he lacks the capacity to take the decision to which it relates. Some American legislation permits patients to revoke their advance directives even though they lack the capacity to do so.[100] Our view, however, is that if a patient is found to be incapable of understanding in broad terms what revocation involves, even when given the benefit of the presumption of capacity, he should not be able to make an effective revocation. Since revocation is a legal transaction, rather than a decision whether to give or withhold consent to medical treatment, we consider that the appropriate test of capacity to revoke should be that proposed in Consultation Paper No.128. Although the test of capacity proposed in that paper is the same as that proposed in this paper, our consultation exercise may suggest that there should be some differences.

3.33 To avoid problems of proof, the Manitoba and Newfoundland Law Reform Commissions considered that the oral revocation of health care directives should not be permitted. A revocation must be written and witnessed, or the directive must be destroyed with the intention of revoking it.[101] The BMA recommended that directives which no longer represent the person's views should be destroyed rather than amended[102] and we agree that the safest way to revoke an advance directive will be to destroy all copies of it. However it is important that patients should be able to change their minds with a minimum of formality. We propose that it should be possible

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[100] For example, the California Natural Death Act 1976, s.7189, provides that a directive may be revoked without regard to the patient's "mental state or competency".

[101] Manitoba LRC, Report No.74, p.16; Newfoundland LRC, WP6, p.80.

[102] *Statement on Advance Directives* (1992), p.11.

to revoke orally at any time when the maker has the capacity to do so.[103] We invite comment on any practical difficulties this may cause.

Automatic revocation after a fixed period

3.34 The BMA recommended that advance directives should be updated at regular intervals. Five years was suggested. It was said that documents which were unrevised after many years, despite changing circumstances, could only give the most general of indications of the patient's ultimate views.[104] It is clearly desirable that the instructions in an advance directive should be regularly reviewed, but there is a danger that automatic revocation after a fixed period might frustrate the intentions of those making them.[105] We propose that, unless the maker explicitly provides that it is to have limited duration, an unrevoked anticipatory decision should operate for as long as it is applicable. We provisionally propose that:

> **5. An anticipatory decision may be revoked orally or in writing at any time when the maker has the capacity (according to the test proposed in Part III of Consultation Paper No.128) to do so. There should be no automatic revocation after a period of time.**

The protection of treatment providers

3.35 It might be useful to clarify the liability of treatment providers who act in accordance with an anticipatory decision.[106] Under the current law, we consider it unlikely that liability would be incurred for acts reasonably performed in accordance with a patient's valid anticipatory decision. Legitimate doubt may remain, however, in

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[103] *The Living Will* (1988), p.59; Alberta LRI, Report for Discussion No.11, p.55.

[104] *Statement on Advance Directives* (1992), p.7.

[105] Automatic revocation has been widely rejected. See *The Living Will* (1988), p.59; Alberta LRI, Report for Discussion No.11, p.55; Newfoundland LRC, WP6, p.78.

[106] See Newfoundland LRC, WP6, p.93; Manitoba LRC, Report No.74, p.19.

relation to cases where an anticipatory decision is subsequently shown to have been invalid. An example would be where it is later shown that the decision had already been revoked before it was acted on. We provisionally propose that:

6. **A treatment provider who acts in accordance with an apparently valid and continuing anticipatory decision should only be liable to any civil or criminal proceedings if he or she does so in bad faith or without reasonable care.**

The protection of incapacitated patients

3.36 The effect of concealing, destroying or altering an advance directive, or of producing a document purporting to represent another person's anticipatory decision, might be extremely serious. A suitably drafted offence is needed to discourage such activity.[107] We therefore provisionally propose that:

7. **It should be an offence to falsify or forge an advance directive; or to conceal, alter or destroy a directive without the authority of its maker. These offences should apply to a written revocation of an advance directive as they do to the directive itself.**

[107] See, for example, Newfoundland LRC, WP6, p.94; Manitoba LRC, Report No.74, p.20.

A statutory authority to treat

3.37 Where a patient who is incapacitated has not made an applicable anticipatory decision someone else will have to decide whether or not any particular medical treatment should be administered or withdrawn.

The present law

3.38 In *Re F*,[108] the House of Lords considered the position of those who are charged with the care of an incapacitated patient and with the responsibility of deciding whether treatment is merited and, if so, what the treatment should be. Lord Jauncey said that if they take such decisions solely in the patient's best interests, and if their approach and execution is such as would be adopted by a responsible body of medical opinion skilled in the particular field of diagnosis and treatment concerned, they will have done all that is required of them and their actions will not be subject to challenge as being unlawful.[109] Lord Goff said that, in making decisions about treatment, a doctor must act in the best interests of the patient, and must act in accordance with a responsible and competent body of relevant professional opinion.[110] For this reason, Lord Donaldson has said that if the patient has made no decision, and is in no position to make one, doctors have both the right and the duty to treat in accordance with what in the exercise of their clinical judgment they consider to be in the patient's best interests.[111]

Criticisms of the present law

3.39 The view that the best interests of the patient should be a matter of "clinical judgment" has been criticised. It has been suggested that *Re F* "can be viewed with

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[108] [1990] 2 A.C. 1.

[109] *Ibid.*, at pp.83-84.

[110] *Ibid.*, at p.78. Lord Goff made it clear that he was referring to the principles set down in *Bolam* v. *Friern Hospital Management Committee* [1957] 1 W.L.R. 582.

[111] *Re T* [1992] 3 W.L.R. 782, 798.

disquiet as yet another example of the House of Lords' willingness to hand over to the doctors an inappropriate degree of unsupervised power over the patient on the basis of 'doctor knows best'".[112] It has been argued that combining the best interests of the patient with *Bolam* is "medical paternalism run amok"[113] and that little room is left for safeguards against treatment whose efficacy, safety, or morality is open to dispute.[114] One critic has asked whether it is imaginable "that any other group of people could have their *best* interests restated as merely the right not to have others make negligent decisions in relation to them."[115] It has also been said that the incapable patient "should be entitled to insist not merely on non-negligent treatment, but treatment which in all the circumstances is in his or her best interests".[116] Similar concerns were strongly represented in the responses we received to Consultation Paper No.119 and Lord Mustill has expressed reservations about the application of the *Bolam* principle to decisions on the best interests of an incapacitated adult.[117]

A statutory authority for treatment providers

3.40 Although we recognise that there is considerable concern that decisions should not be left to a single professional, or even to the medical profession as a whole, the treatment provider will inevitably have an important role in any decision-making and will be responsible for carrying out the treatment decided on. In Consultation Paper No.128 we proposed an explicit, but limited, statutory authority for those caring for an incapacitated person. Although the common law authority to provide medical treatment is more firmly established, we consider that the same approach is an appropriate starting point in relation to medical treatment. Therefore we provisionally propose that:

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[112] C. Lewis, "Medical treatment in the absence of consent", (1989) 30 L.S.Gaz. 32, p.33.

[113] M. Jones, "Justifying medical treatment without consent", (1989) 5 P.N. 178, p.180.

[114] L. Gostin, *Mental Health Services - Law and Practice* (1986), para. 20.16.4.

[115] D. Carson, "The Sexuality of People with Learning Difficulties" (1989) 6 J.S.W.L. 355, p.372.

[116] L. Gostin, *Mental Health Services - Law and Practice* (1986), para. 20.16.4.

[117] *Airedale NHS Trust* v. *Bland* [1993] 2 W.L.R. 316, 399.

8. **A treatment provider should be given a statutory authority (subject to the other proposals contained in this paper) to carry out treatment which is reasonable in all the circumstances to safeguard and promote the best interests of an incapacitated person [or a person whom he or she has reasonable grounds for believing to be incapacitated].**

We invite views on whether a treatment provider should only be required to have reasonable grounds for believing the person to be incapacitated.[118]

Limits to the statutory authority

3.41 Anyone who acts under this statutory authority will be subject to the criminal law[119] and the law of tort.[120] In addition, under our proposals, a forum would be available to resolve any disputes or uncertainties about a particular proposed treatment.[121] However, as in Consultation Paper No.128,[122] we consider that there should be a number of exclusions and limitations on the scope of what can and cannot be done without application to this independent forum.

3.42 First, we suggested above that an applicable anticipatory decision might be as binding upon treatment providers as a contemporaneous decision of a capable patient.[123] The statutory authority would not permit an anticipatory refusal to be overridden. Similarly, if a person has been appointed with the authority to refuse a

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[118] See para. 3.72 below.

[119] For example, in relation to homicide, see para. 1.13 above, and in relation to abortion, see para. 6.22 below.

[120] See paras. 3.71-3.72 below.

[121] See Part IV below.

[122] Paragraphs 2.16-2.19.

[123] Paragraph 3.13 above.

treatment of the kind in question,[124] it would not usually be reasonable to override such a refusal. Finally, if an order prohibiting a particular treatment has been obtained under an appropriate jurisdiction, the statutory authority would be subject to that order. There may, however, be circumstances in which it is necessary to provide treatment in order to preserve the patient's life or to prevent irreversible deterioration of health for long enough to seek a ruling from a judicial forum. Therefore we provisionally propose that:

9. Unless it is essential to prevent loss of life or irreversible deterioration of health while an issue is referred to a relevant judicial forum, the statutory authority should not permit the carrying out of any treatment contrary to a valid anticipatory refusal by the person who is now incapacitated, a refusal of consent by a person with the authority to do so, or a prohibition by a judicial forum.

3.43 Secondly, there are some decisions which are so serious or controversial that they require independent supervision. For example, under the current law "as a matter of good practice" the approval of the High Court should be obtained before "non-therapeutic" sterilisation operations are performed upon incapacitated patients. There will continue to be a category of decisions which require the involvement of a judicial forum.[125] There may also be some decisions for which some lesser form of independent approval is sufficient,[126] as already happens under Part IV of the Mental Health Act 1983 with the system of "second opinion doctors" appointed by the Mental Health Act Commission. Therefore we provisionally propose that:

10. The statutory authority should not permit the taking of any step for which the approval of the judicial forum or some other person is required (see Part VI below) unless that approval has been obtained.

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[124] See paras. 4.20-4.29 and Part V below.

[125] See paras. 6.1-6.15 below.

[126] See para. 6.30-6.34 below.

3.44 The final exclusion which we consider appropriate relates to those who are objecting to a proposed treatment. We consider that where an incapacitated person objects to a treatment option then he should not be forced to comply with it without some independent confirmation that the patient is actually incapacitated and that the benefits of the treatment outweigh the harm which even an incapacitated patient may suffer if treatment is forced upon him. As well as being an important safeguard for the patient, independent evidence of this sort may help to protect the treatment provider against future legal challenge.[127]

3.45 In Consultation Paper No.128 we proposed that a person who was objecting should not be forced to comply with a decision without the independent authorisation of the judicial forum unless it was essential to prevent an immediate risk of serious harm to that person or others.[128] We propose to adopt the same approach in relation to medical treatment. Where treatment is immediately necessary, so that it is impractical to follow the necessary procedure, we consider that a doctor should be able to provide whatever treatment is reasonably required. Therefore we provisionally propose that:

> **11. The statutory authority should not permit the carrying out of any treatment to which the incapacitated person objects, unless such treatment is essential to prevent an immediate risk of serious harm to that person or others.[129]**

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[127] Staughton L.J. has discussed the serious problems under the current law for those faced with an apparent refusal of treatment. Difficulties did not arise so much when the choice lay between consent and no decision since the surgeon may lawfully operate in either case, but where the choice is between no decision and refusal the surgeon will be liable in damages if he operates when there is a valid refusal of consent, and liable in damages if he fails to operate in accordance with the principle of necessity when there was no valid decision by the patient. The medical profession, in the future as in the past, must bear the responsibility unless it is possible to obtain a decision from the courts (*Re T* [1992] 3 W.L.R. 782, 805). In a potentially life threatening situation or one in which irreparable damage to the patient's health is to be anticipated, where doctors or hospital authorities are faced with a refusal by an adult patient to accept essential treatment and they have real doubts as to the validity of that refusal, they should in the public interest and that of their patient, at once seek a declaration from the courts as to whether the proposed treatment would or would not be lawful (*Ibid.*, at p.798 *per* Lord Donaldson M.R.).

[128] Paragraph 2.18.

[129] We do not consider that the foetus carried by an incapacitated pregnant woman should be regarded as an "other" for this purpose.

3.46 Lord Brandon's statement that treatment will be in a patient's best interests if, but only if, it is carried out in order either to save his life, or to ensure improvement or prevent deterioration in his physical or mental health[130] has been said to restrict a doctor to considering "medical factors".[131] In the same case, however, Lord Goff spoke of cases which involve "more than a purely medical opinion"[132] and Lord Keith has explained that the ground of the decision of the House of Lords in *Re F* was that the operation would be in the patient's best interests "because her life would be fuller and more agreeable".[133]

3.47 We do not believe that the patient's interests should be limited to "medical" interests, although these are certainly important. The values of "normalisation" and the "least restrictive alternative" which received support from those who responded to Consultation Paper No.119 are based upon individual interests which are not "medical". In *Re F*, Lord Donaldson said in the Court of Appeal that doctors exercising a right of choice on behalf of a patient should apply the same principles as those which would be applied by a "reasonable" adult considering his own medical treatment.[134] "Non-therapeutic" treatments which are not intended to promote the patient's health may require separate provision[135] but, in deciding whether and in what way to treat a patient, doctors undoubtedly do consider such things as the happiness, freedom, and dignity of the patient, which cannot be regarded as purely medical interests. We do not consider that the range of relevant factors should be restricted.

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[130] *Re F* [1990] 2 A.C. 1, 55.

[131] A. Grubb and D. Pearl, "Sterilisation - Courts and Doctors as Decision Makers", [1989] C.L.J. 380, p.382. See also D. Morgan [1990] J.S.W.L. 204, p.206.

[132] [1990] 2 A.C. 1, 78.

[133] *Airedale NHS Trust* v. *Bland* [1993] 2 W.L.R. 316, 361 *per* Lord Keith.

[134] [1990] 2 A.C. 1, 18. This does not mean that the decision reached should be the same decision which a "reasonable patient" would make. See paras. 3.49-3.50 below.

[135] See Part VI below.

3.48 Professor Gostin argues that it is necessary to take into account the "social implications" of a decision, and whether there are less restrictive or less intrusive alternatives.[136] In a recent case,[137] Sir Stephen Brown P. said that before the carrying out of certain operations on an incapacitated adult without the involvement of a court, two doctors should certify that, as well as being in the best interests of the patient, there is no practicable, less intrusive means of treating the patient's condition. Professor Gostin was concerned that the complicated personal, social, and moral judgments involved go well beyond the expertise of a single doctor.[138] The provision of a second medical opinion will not necessarily meet this concern,[139] but we consider that it would be valuable to include an explicit requirement that, in determining what is in a patient's best interests, alternative treatments should be considered, and less restrictive and intrusive alternatives preferred.

3.49 It has been argued that the best interests test is based on what "the reasonable patient" would want or need and is therefore often a fiction which overlooks the features of the individual patient.[140] However, in *Re F* Lord Goff in the House of Lords agreed[141] with Lord Donaldson M.R. in the Court of Appeal that the law required the doctor to exercise a "right of choice" in relation to an incapacitated adult in exactly the same way as a court or reasonable parent would do in relation to a child, "making due allowance for the fact that the patient is not a child".[142] In a case concerning a child, *Re J*,[143] the issue was whether distressing and invasive treatment

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[136] *Mental Health Services - Law and Practice* (1986), para. 20.16.4.

[137] *Re GF (Medical Treatment)* [1992] 1 F.L.R. 293.

[138] *Mental Health Services - Law and Practice* (1986), para. 20.16.4.

[139] In later sections we consider the involvement in the decision-making process of relatives and others (paras. 3.59-3.70), substitute decision-makers appointed by the person concerned (Part V) or on his behalf (paras. 4.20-4.29). For particularly serious decisions we consider the need for medical second opinions or an independent review (Part VI).

[140] M. Brazier, *Medicine, Patients and the Law* (2nd ed., 1992), p.110.

[141] [1990] 2 A.C. 1, 77.

[142] *Ibid.*, at p.18.

[143] *Re J (A Minor)(Wardship: Medical Treatment)* [1991] Fam. 33.

should be given to a very severely handicapped baby, taking into account the pain and suffering which would result. The child's doctors considered that treatment would not be in the child's best interests. Lord Donaldson M.R. emphasised the need to adopt the "assumed point of view" of the patient.[144] In the same case, Taylor L.J. agreed that the test must be what the child in question, "if capable of exercising sound judgment", would choose, taking into account the strong instinct to preserve life which even a severely handicapped child might possess in circumstances which an external decision-maker would consider unacceptable.[145] On the other hand, Balcombe L.J. said that the court should adopt the same attitude as a reasonable and responsible parent.[146] We express no view as to the most appropriate standard but, as Ward J. has said, even where a court adopts the "wholly objective" standard of the ordinary mother and father, the court is looking not at an *ordinary* child, but at a particular child, and in that sense, it is a subjective standard.[147]

3.50 In relation to adults, a number of respondents considered that the introduction of a substituted judgment standard, asking what the patient would have chosen,[148] was not suitable when applied to cases where a patient has never had the capacity to make decisions.[149] Nevertheless, a person who has never had the capacity to make decisions, or even the ability to express views, is still an individual and his unique reactions to the world may be identifiable. We consider that in determining the best interests of an incapacitated adult it is appropriate to attempt to consider the

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[144] *Ibid.*, at p.46.

[145] *Ibid.*, at p.55.

[146] *Ibid.*, at p.50.

[147] *Re E (A Minor) (Wardship: Medical Treatment)* [1992] 2 F.C.R. 219, 226.

[148] See Consultation Paper No.119, paras. 4.22-4.23.

[149] In *Airedale NHS Trust* v. *Bland*, [1993] 2 W.L.R. 316, 395-396, Lord Mustill said that while an attempt to infer what choice the patient would have made from his general feelings is "in many ways attractive", there are "obvious dangers" which justify an approach such as that in *Re Storar* (1981) 420 N.E. 2d. 64. In that case it was said that it was unrealistic to attempt to determine whether the patient would want to continue life-prolonging treatment when he had always been totally incapable of understanding or making a reasoned decision about medical treatment (in I. Kennedy and A. Grubb, *Medical Law: Text and Materials* (1989), p.1101).

consequences of a decision from the patient's point of view as far as possible. As Lord Goff has said, although a substituted judgment test does not form part of English law, in the application of the best interests test anything relevant may be taken into account, and in a case such as *Re J*, the personality of the patient may be taken into account.[150]

The incapacitated person's views

3.51 The child in *Re J* was never able to express any views but it follows from what has been said above that an incapacitated patient's views and feelings ought to be taken into account wherever they can be ascertained. As Professor Gostin says, patients may enunciate current opinions which, while not wholly lucid, may express their feelings and represent powerfully important evidence to consider in deciding about treatment.[151] It has been said that the wishes of a mentally incapable *child* "must be a very material factor",[152] and those of an adult should be at least as significant.

Views expressed prior to incapacity

3.52 Many of those who responded to Consultation Paper No.119 supported the use of a substituted judgment standard where possible. This is generally considered appropriate only for patients who were once capable of making decisions, with known preferences or idiosyncrasies.[153] We have suggested above that the identifiable views and preferences of a person who has always been incapacitated should be a significant factor in determining the person's best interests and that a person's known preferences when he was capable may constitute an anticipatory decision. However, views and preferences which are not "clearly established" and "applicable to the circumstances" which have arisen may still be relevant to a decision.

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[150] *Airedale NHS Trust* v. *Bland* [1993] 2 W.L.R. 316, 375 *per* Lord Goff.

[151] *Mental Health Services - Law and Practice* (1986), para. 20.16.4.

[152] *Re W* [1992] 3 W.L.R. 758, 776 *per* Balcombe L.J.

[153] M. Brazier, *Medicine, Patients and the Law* (2nd ed., 1992), p.110.

3.53 In *Re T*, Lord Donaldson said that consultation with a patient's "next of kin" might reveal information as to the personal circumstances of the patient and as to the choice which the patient might have made, if he had been in a position to make one. However, he added that neither these personal circumstances, nor a speculative answer to the question "What would the patient have chosen?", could bind the doctor and they could not justify him in acting contrary to a clearly established anticipatory refusal to accept treatment. They were factors to be taken into account by the doctor in forming a judgment about the patient's *best interests*.[154] Lord Donaldson gave the example that a doctor would avoid or postpone blood transfusions for a known Jehovah's Witness for as long as possible, even where there was no evidence of a treatment refusal. In such circumstances, where a patient has not made a decision (nor appointed someone to do so[155]), we do not consider that it would be acceptable to oblige a doctor to withhold treatment because others believe that this is what the patient would have decided.

3.54 As Lord Donaldson points out, where the patient's preferences do not constitute an anticipatory choice, attempting to decide what he would have chosen will be a matter of speculation. Patients may have expressed an opinion about the treatment of other people, or about their own treatment, in circumstances which were similar to but not the same as the present situation. They might have religious beliefs from which their views can be deduced, as in Lord Donaldson's example. It was pointed out in the American case of *Re Conroy*[156] that the significance of the patient's previous views will vary greatly according to their remoteness, consistency, thoughtfulness and specificity. The weaker the basis for substituted judgment, and the more speculative it is, the greater will be the significance of other factors in determining the patient's best interests.

3.55 In Alberta it has been proposed that decisions should be those the patient would have made if "competent", and according to what is believed to be in the patient's best

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[154] [1992] 3 W.L.R. 782, 787.

[155] See Part V below.

[156] (1985) 486 A.2d 1209.

interests only if that is not possible.[157] On the other hand, in recent legislation in Ontario[158] and in proposals in Manitoba and Newfoundland,[159] decisions should be made according to the decision-maker's view of the patient's best interests, after taking into account the patient's beliefs, values and wishes. We favour the second approach, which received influential support from those who responded to Consultation Paper No.119, and which was proposed in Consultation Paper No.128.[160] We have already proposed that the views of an incapacitated person should be considered, and we propose that, in determining the patient's best interests, any views expressed and values held by the patient before the onset of incapacity should be considered.

3.56 Accordingly, we provisionally propose that:

12. In deciding whether a proposed medical treatment is in the best interests of an incapacitated person, consideration should be given to:

(1) the ascertainable past and present wishes and feelings (considered in the light of his or her understanding at the time) of the incapacitated person;

(2) whether there is an alternative to the proposed treatment, and in particular whether there is an alternative which is more conservative or which is less intrusive or restrictive;

(3) the factors which the incapacitated person might be expected to consider if able to do so, including the likely effect of the treatment on the person's life expectancy, health, happiness, freedom and dignity.

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[157] Alberta LRI, Report for Discussion No.11, p.69.

[158] Consent to Treatment Act 1992, s.13.

[159] Manitoba LRC, Report No.74, p.6; Newfoundland LRC, WP6, pp.84-85.

[160] Paragraphs 2.14-2.15.

3.57 Although we have suggested that the factors which the person might be expected to consider if capable of doing so should be considered, it may be that some qualification is required. Although the interests of family members may well be among the factors which capable patients consider, it is questionable whether they should be considered by a person deciding on behalf of an incapacitated person. In *Re F* Lord Jauncey said that convenience to those charged with the care of an incapable patient should never be a justification for the decision to treat.[161] However, Professor Brazier argues that it is dubious whether it is ever possible to divorce the interests of the individual patient entirely from the interests of those who care for him. The interests of the patient must be the predominant interest to be considered, but, she suggests, if the interests of others will inevitably be considered "would it not be better to do so openly and not hide behind a pious fiction of best interests"?[162]

3.58 The Mencap working party suggested that the impact of a decision on the patient's relatives or friends should be taken into account, but that there should be stringent safeguards before their interests could override the patient's self-regarding interests.[163] The concern that the sterilisation of incapacitated women might be prompted by the convenience of those caring for them is one of the reasons why safeguards are desirable before such operations are carried out. Similar considerations may apply in cases such as organ donation, or hysterectomies for the purpose of menstrual management.[164] In more routine cases it may be right to stress that if the interests of others are involved they should be recognised openly. However, we find it difficult to see how to acknowledge this where it is inevitable, without encouraging it where it is not. We consider that the interests of other people should be relevant only

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[161] [1990] 2 A.C. 1, 83.

[162] M. Brazier, *Medicine, Patients and the Law* (2nd ed., 1992), p.109.

[163] *Competency and Consent to Medical Treatment* (1989), p.11.

[164] See Part VI.

to the extent that they affect the interests of the patient. Hence we provisionally propose that:

13. The interests of people other than the incapacitated person should not be considered except to the extent that they have a bearing on the incapacitated person's individual interests.

The involvement of relatives and others

3.59 Although we have proposed that the interests of family-members and those who care for the incapacitated person should not be relevant factors when making decisions about medical treatment, this does not mean that such people should not have an important role in the decision-making process. Involving those who know the person well may be a better way to ensure that decisions are made as the person concerned would have wanted than introducing a substituted judgment test which is applied by those with a limited knowledge of the patient.

The present law

3.60 Under the current law, legal responsibility ultimately rests with the doctor who administers treatment. However, in *Re F*, Lord Goff said that in practice others besides the doctor would be involved.[165] Sometimes, consultation with a specialist or specialists would be required and particularly where the decision involves more than a purely medical opinion, an inter-disciplinary team would participate in the decision. Surely, he said, it must be good practice to consult relatives and others who are concerned with the care of the patient.[166] The BMA *Interim Guidelines* say that doctors should discuss a proposed "serious treatment" with "the patient's health care team; - a relative/s or friend/s of the patient who, in the opinion of the doctor, has an

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[165] [1990] 2 A.C. 1, 78.

[166] This guidance is reproduced in the NHS *Guide to Consent*, p.10, which notes that consultation with the patient's nearest relative or friend should be with the consent of the patient where this is possible.

interest (and especially those with whom the patient resides) in the well being of the patient; - any other professionals involved with the patient's care either in hospital or in the community".[167]

3.61 In *Re J*, Lord Donaldson M.R. said that doctors "nowadays recognise that their function is not a limited technical one of repairing or servicing a body" and that they "are treating people in a real life context." This, he said, enhanced the contribution which a child's parents or the court can make towards reaching "the best possible decision in all the circumstances."[168] The same reasoning might be applied to the involvement of the relatives of an incapacitated adult. In *Re T*, Lord Donaldson said that although the "next of kin"[169] has no legal right either to consent or to refuse consent on behalf of an adult patient, it may not be undesirable to seek such consent if the interests of the patient will not be adversely affected by any consequential delay. The existence of an anticipatory decision, or information as to the personal circumstances of the patient and as to the choice which the patient might have made, if he had been in a position to make one, might be revealed.[170]

A duty to consult

3.62 A number of respondents to Consultation Paper No.119 supported the introduction of a duty to consult relatives. The Scottish Law Commission has recently proposed that doctors should be required to consult near relatives "so far as is reasonably practicable", giving them sufficient information about the patient's condition, the proposed treatment and its effects, and to have regard to their views. It proposed that the nearest relative should be the first person reasonably available from: husband, wife or cohabiting partner; a child over 18 years of age; a parent; a brother or sister.

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[167] Page 7. For the definition of "serious treatment" see below para. 6.32, n.76.

[168] [1992] Fam. 33, 41.

[169] It has been noted that there may be a widespread but mistaken belief that the identity and role of the patient's "next of kin" is defined by law, C. Schlyter, *Advance Directives and AIDS* (1992), p.72.

[170] [1992] 3 W.L.R. 782, 787.

There should be no statutory obligation to seek the views of close friends, persons caring for the patient, or proprietors of institutions in which the parent is normally resident, although there would be nothing to stop this happening.[171]

3.63 There would be nothing to stop the treatment provider consulting people other than the nearest relative, and giving weight to their views. Indeed, failure to obtain the advice of other professionals or to ask those close to the patient for significant information might sometimes constitute negligence. Less weight could be given to the views of a person whose involvement with the incapacitated person was limited, or whose interests conflicted with those of the incapacitated person.[172] We do not consider that consultation would be necessary on every occasion before the provision of routine treatment, and it could take place in relation to a "treatment plan".[173]

3.64 The "nearest relative" has an important role in the Mental Health Act 1983. In identifying nearest relatives, relatives with whom the patient ordinarily resides or with whom he or she last ordinarily resided before admission to hospital as an in-patient are preferred.[174] A person who is not a relative, with whom the patient has ordinarily resided for five years, may be treated as the nearest relative.[175] Although the Scottish Law Commission considered the similar provisions of the Mental Health (Scotland) Act 1984 unduly complex for the purposes of medical treatment,[176] as a basis for

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[171] Discussion Paper No.94, paras. 3.16-3.21.

[172] We are not suggesting that any duty to consult should be enforceable by an action in tort for a breach of statutory duty.

[173] The *Code of Practice*, para. 15.6, suggests that it is important to discuss a treatment plan with "the appropriate relatives concerned about a patient" but adds "but only with his consent". The BMA advises that doctors may disclose information to an extent necessary for an incapacitated patient's interests, but notes that some incapacitated patients "may express their own valid and competent opinions about the involvement of relatives in their treatment", *Interim Guidelines*, p.4.

[174] Mental Health Act 1983, s.26(4).

[175] *Ibid.*, s.26(7).

[176] Scottish Law Commission Discussion Paper No.94, para. 3.18.

discussion we believe that the Mental Health Act definition should be the starting point. Therefore we provisionally propose that:

> **14. A treatment provider should be under a duty to consult the incapacitated person's "nearest relative" (as defined in the Mental Health Act 1983, section 26) so far as is reasonably practicable, to give that person sufficient information (including information about the patient's condition, the proposed treatment and the reasonably foreseeable consequences of providing or not providing treatment) and to have regard to that person's views.**

3.65 However if the "nearest relative" is not available or is unwilling to be consulted, we consider that the next person on the list of relatives should be the nearest relative for this purpose. Therefore we provisionally propose that:

> **15. If the nearest relative is not reasonably available, or is incapacitated, or is unwilling to be consulted, that person should be disregarded for the purpose of determining the identity of the nearest relative.**

3.66 A significant number of people may prefer that a different relative, or someone who is not a relative, should be consulted instead of their "nearest relative". Most of the doctors surveyed in the research carried out in the HIV and AIDS field said that, if communication with the patient was not possible, they would normally turn to someone who knew the patient. However, 25 out of 35 said that it was not always obvious who should be consulted. 91% of the doctors considered that it would be helpful if the patient had decided in advance to whom the doctor should turn.[177] A patient may name a "next of kin,"[178] but it might be valuable to provide an opportunity to record the choice in a more formal way with specified consequences. 91% of the patients surveyed would consider naming a "health care proxy". Many

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[177] C. Schlyter, *Advance Directives and AIDS* (1992), pp.32-33.

[178] But see para. 3.61, n.169, above.

(55%) wanted the proxy to be a "sole decision-maker" but 42% wanted the person named to act as an adviser to the doctor.[179] A mechanism by which a person may choose someone, whom we call a "medical treatment attorney", to give or withhold consent on his behalf when incapacitated is considered in Part V, but we consider that it should also be possible to make an anticipatory choice about who is to be consulted, so that the person named would take priority over the nearest relative. Advance directives could be used for this purpose. We provisionally propose that:

16. Where the patient has named another person to be consulted about treatment decisions should he or she become incapacitated, the person named should be the "nearest relative" for the purpose of the duty to consult.

3.67 It might also be appropriate for an acting nearest relative to be appointed on the person's behalf. Section 29 of the Mental Health Act 1983 contains a number of grounds upon which a county court may do this for the purposes of that Act. Since the function of the nearest relative is limited to consultation we do not believe that it is necessary to permit a replacement to be appointed on the grounds that the person has acted unreasonably[180] or without due regard to the welfare of the incapacitated person.[181] A ground that the person is incapable of acting as a nearest relative by reason of mental disorder is also unnecessary in view of paragraph 3.65 above. The remaining ground is that there is no nearest relative, or the nearest relative cannot be ascertained. We invite comment on whether there should be any other grounds for appointing an acting nearest relative and we provisionally propose that:

17. Any suitable person who consents to perform the functions of a "nearest relative" for the purposes of the duty to consult may be appointed if the incapacitated person has no "nearest relative", or it

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[179] C. Schlyter, *Advance Directives and AIDS* (1992), pp.16-17.

[180] As in s.29(3)(c).

[181] As in s.29(3)(d).

is not reasonably practicable to ascertain whether he or she has such a relative, or who that relative is.

A duty to obtain consent?

3.68 A few respondents supported the introduction of a duty to seek the consent of relatives or others caring for an incapacitated patient. Recent legislation in Ontario provides that consent may be given or refused by the first person from a list of relatives, who is at least 16 and is available, capable and willing to give or refuse consent. The list includes: the patient's spouse or partner; child; parent; brother or sister; and any other relative.[182]

3.69 The difficulty with such schemes is that no statutory list will ever identify the most appropriate relative in every case. While many people might trust their spouses to make decisions for them, fewer will have the same confidence in their nephews. The fact that a person is the patient's next of kin may not be enough if there has been no contact with the patient for twenty years.[183] In the proposals in Alberta, relatives would not have authority to make health care decisions on the incapacitated person's behalf unless they have had personal contact with the patient at some time during the preceding twelve months.[184] Under legislation in New South Wales, except in an emergency the consent of the "person responsible" is required for all medical treatment other than treatments such as sterilisation which require the consent of the Guardianship Board.[185] The person responsible is the patient's spouse, or if there is no spouse, the person who has care of the patient, unless the patient lives in institutional care, in which case it is the person who cared for him immediately before the admission.[186]

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[182] A guardian, a representative, or an attorney with authority to consent to the treatment, takes precedence over the relatives on the list. A similar scheme has been proposed in Alberta (Alberta LRI, Report for Discussion No.11, pp.60-61).

[183] M. Brazier, *Medicine, Patients and the Law* (2nd ed., 1992), p.103.

[184] Alberta LRI, Report for Discussion No.11, p.63.

[185] Disability Services and Guardianship Act 1987, Part V.

[186] Section 3.

3.70 We are not at present persuaded that there is a need to introduce a scheme which gives relatives or carers an automatic authority to consent to, and also to refuse, medical treatment on behalf of an incapacitated person. Although one respondent argued that relatives might only be provided with sufficient information if a treatment provider was required to seek their consent, we believe that an appropriately formulated duty to consult relatives would be a better response to this problem. In New South Wales it has been suggested that incapacitated patients may sometimes not receive treatment because of the formalities required to obtain the consent of the person responsible.[187] The President of the Victorian Guardianship and Administration Board has suggested that if someone automatically has the legal authority to consent it is too easy for doctors just to accept that person's consent without making a proper assessment of the risks involved in a proposed treatment.[188] In Consultation Paper No.128 we rejected an automatic authority for relatives,[189] and we also do so in the context of medical treatment. The limited authority which we proposed for those who have care of an incapacitated person was intended to be no more than was required to allow the incapacitated person to be appropriately cared for.[190] We do not believe that the interests of the incapacitated person require this to include an authority to give or refuse consent to medical treatment.[191] Therefore we provisionally propose that:

18. There should be no duty to obtain the consent of another person to the medical treatment of an incapacitated person simply on the basis of a family relationship.

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[187] K. Rosser, "Medical Consent - Legislate or Leave Alone?" (1989) unpublished paper, pp.19-20.

[188] Quoted *ibid.*, p.16.

[189] Paragraph 2.9.

[190] Paragraphs 2.10-2.13.

[191] For an argument that the "natural" role of the family in making decisions for an incapacitated adult should be recognised see A. Grubb, in A. Grubb (ed.), *Choices and Decisions in Health Care* (1993), pp.38-48.

3.71 The effect of the decision of the House of Lords in *Re F* is that the potential liability of those who provide treatment to an incapacitated person is determined by the application of the principles of the law of negligence. Although a number of our respondents were concerned that the *Bolam* test of medical negligence is insufficiently strict to protect patients from unnecessary or inappropriate treatment, we do not consider that a negligence action after treatment has taken place is the most useful safeguard for an incapacitated patient's rights. There may be some decisions which require special safeguards[192] but, in general, we prefer to concentrate on providing those (including the patient) who are concerned about a particular treatment with an opportunity to object before it takes place.[193] Where treatment has proceeded without such objection, the treatment provider should not be exposed to liability if he has acted according to a reasonably held view of the patient's best interests after considering the relevant factors and consulting the appropriate people. This should be so even if others in the same position might have acted differently.

3.72 There may be more difficulty where a patient is mistakenly treated as incapacitated, since under the current law even a reasonable mistake would not be a defence to an action for battery.[194] We have already invited comment on whether those who the treatment provider has reasonable grounds for believing to be incapacitated should be included in the statutory authority.[195] If such people are included, a person might be treated under the statutory authority because he is mistakenly believed to be incapacitated and the reasonable treatment provider would have a defence. However if the patient is actively objecting to the proposed treatment

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[192] See Part VI below.

[193] See Part IV below.

[194] *Clerk & Lindsell on Torts* (16th ed., 1989), para. 1-189.

[195] Paragraph 3.40 above.

the statutory authority would be subject to a requirement to obtain independent confirmation that the patient is incapacitated.[196] We provisionally propose that:

19. **A person who provides medical treatment in pursuance of the proposed statutory authority should only be liable to any civil or criminal proceedings if he or she does so in bad faith or without reasonable care.**

[196] See paras. 3.44-3.45 above and paras. 4.31-4.32 below. If a patient who is not incapacitated acquiesces to treatment after an appropriate explanation has been given his consent may be implied in some circumstances.

PART IV

A JUDICIAL FORUM

4.1 In most cases consultation will produce agreement among professionals, those concerned with the welfare of the patient, and the incapacitated person to the extent that he can express a view, but occasionally disputes may require authoritative resolution. In other cases there may be uncertainty about the patient's capacity, the scope or validity of an anticipatory decision, or whether or not a particular treatment is in his best interests. Reference to a judicial forum can ensure that decisions are made properly, and are seen to be made properly, and protect those providing the treatment from criticism or future liability. In addition, there may be a category of decisions which are so serious that the involvement of a judicial body is always required.[1]

The present law

4.2 Judicial involvement with medical decision-making in relation to children is possible through the High Court's inherent jurisdiction or the statutory jurisdiction provided by the Children Act 1989. In relation to incapacitated adults, the House of Lords in *Re F* concluded that no court could approve or disapprove proposed medical treatment[2] and the court's role is limited to making a declaration that the particular course of action proposed is lawful.[3] Therefore the legal question ("unlike the question which would arise if there were a parens patriae jurisdiction") is not whether or not a particular treatment is in the person's best interests, but whether the responsible professionals have made a reasonable and bona fide decision in accordance with a

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[1] This issue is considered in Part VI.

[2] [1990] 2 A.C. 1, 63.

[3] *Ibid.*, at p.64.

respectable body of medical opinion.[4] A declaration that a proposed course of action is lawful is adequate for some purposes. However, under the ordinary law, treatment will not be unlawful if it is in accordance with a practice accepted as proper by a responsible body of medical opinion skilled in the area in question.[5] Since there may be two or more responsible bodies of medical opinion, a court might be unable to resolve a dispute because it has to declare that it would be lawful to act as proposed by those on either side.

4.3 By contrast, the patient who has the capacity to do so, and parents or courts deciding on behalf of children, do not attempt to decide whether the treatment proposed is in accordance with a responsible body of medical opinion. They attempt to decide whether, in all the circumstances as they see them, the treatment is what seems to them to be "best". Recently Lord Mustill expressed reservations about the application of the *Bolam* principle to decisions concerned with an incapacitated adult's best interests which go beyond questions of diagnosis, prognosis and appraisal and are ethical, not medical. In such questions, he said there was no reason why the opinions of doctors should be decisive.[6]

A new jurisdiction

4.4 We consider that it should continue to be possible to refer decisions which are made on behalf of an incapacitated patient, and questions of the scope or validity of the patient's own decisions, to a judicial forum. However, we consider that the jurisdiction of the judicial forum should be placed on a statutory basis. This would overcome the limitations of the common law, by providing a range of flexible orders in addition to a jurisdiction to make declarations. We envisage that the statutory jurisdiction would have several conceptually distinct functions. First, orders might be made approving or disapproving a particular decision made on behalf of an incapacitated person, or

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[4] *Airedale NHS Trust* v. *Bland* [1993] 2 W.L.R. 316, 386 *per* Lord Browne-Wilkinson.

[5] *Bolam* v. *Friern Hospital Management Committee* [1957] 1 W.L.R. 582.

[6] *Airedale NHS Trust* v. *Bland* [1993] 2 W.L.R. 316, 399.

appointing someone to make decisions on the person's behalf. Secondly, the judicial forum would exercise a declaratory jurisdiction. This would not be concerned with making decisions for the incapacitated person but with establishing and declaring the facts, for example whether a person was incapacitated, or whether an anticipatory decision was "clearly established" and "applicable to the circumstances". These two functions are considered in more detail below. A third possible function for the judicial forum (which we do not at present envisage) would be to overrule otherwise valid anticipatory decisions.[7] We provisionally propose that:

1. **There should be a judicial forum with a statutory jurisdiction:**
   (1) to make orders approving or disapproving the medical treatment of incapacitated patients; and
   (2) to make declarations as to the patient's capacity or the scope or validity of the patient's own decisions.

4.5 A fundamental question is whether the judicial forum should be a court or a tribunal established by statute. A multi-disciplinary body was proposed by a number of the respondents to Consultation Paper No.119, including Mencap, the BMA, the Law Society's Mental Health Sub-Committee and the Mental Health Act Commission. Tribunals could have procedures tailored to the subject matter, and could include members with particular expertise. An appropriate model might be Mental Health Review Tribunals which have medical and lay members, and a legally qualified president.[8] Tribunals may be more informal than courts. Their procedures are less dependent on the parties presenting their cases since tribunal members will take an active part in eliciting relevant material. For this reason legal representation may be unnecessary.[9] On the other hand, courts provide an existing system with established

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[7] For our provisional view that such a power is unnecessary see paras. 3.29-3.31 above.

[8] Mental Health Act 1983, s.65 and Sched. 2.

[9] Mental Health Review Tribunals are the only tribunals for which "assistance by way of representation" is available.

procedures. They may be better suited to respond quickly in an emergency.[10] A system for the provision of investigative reports could be developed and the membership of the court could be drawn from those with experience in a particular type of work. We invite comment on the nature of the judicial forum.

4.6 We do not consider that it is necessary for the judicial forum to be the same body which deals with other aspects of a mentally incapacitated person's personal care and welfare under the proposals in Consultation Paper No.128. A judicial forum dealing with the most difficult questions relating to medical treatment, might be less appropriate for dealing with wider questions of an incapacitated person's life. A person may be incapacitated in relation to one sort of decision, but not another, and the need for judicial involvement is likely to arise in different circumstances. We do not envisage that there would be problems of different fora making inconsistent findings of capacity or incapacity in relation to the same person. The findings of one forum in one respect would be a relevant consideration, but would not be conclusive, for a different forum dealing with a question in relation to a different aspect of the person's life. We invite comment on whether there are any situations where the existence of separate fora would cause practical problems.

4.7 Whether or not a system of tribunals is introduced, there might be a category of cases in which the continued involvement of the High Court is desirable.[11] The statutory jurisdiction available under the Children Act 1989 allows for the transfer of cases between different levels of courts with concurrent jurisdictions.[12] A Mental Health Review Tribunal can state a case for determination by the High Court of any point of law arising before it, and may be compelled to do so.[13] Since we are not

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[10] In *Re T* [1992] 3 W.L.R. 782, at 1.30 a.m. after taking evidence by telephone, Ward J. made a declaration that blood transfusions might lawfully be given.

[11] In a case concerning the sterilisation of a learning disabled 17-year-old, Lord Templeman suggested that decisions which vitally concern an individual but also involve principles of law, ethics and medical practice should be decided by judges of the Family Division, *Re B (A Minor) (Wardship: Sterilisation)* [1988] A.C. 199, 206.

[12] See the Children (Allocation of Proceedings) Order 1991, S.I. 1991, No.1677.

[13] Mental Health Act 1983, s.78(8).

proposing that the High Court's existing jurisdiction to make declarations that a proposed course of action is, or is not, lawful, should be limited that jurisdiction would be concurrent with any statutory jurisdiction exercised by a different forum. We invite comment on the relationship of the judicial forum with the High Court.

4.8 Although we consider that there is a need for a judicial forum, we consider that it is important that a forum is not used merely to provide reassurance for the person providing treatment, or to avoid responsibility for decisions. Judicial involvement should be restricted to cases where it is impossible to proceed without it, or where there is a genuine and serious dispute, between people intimately concerned with the patient or his treatment, which cannot be resolved in any other way.[14] We do not envisage that it will be necessary to seek judicial involvement in many cases. We would welcome comment on the likely number of applications.

4.9 As to the proposed jurisdiction to approve the treatment of an incapacitated person, we consider that the same approach is appropriate in relation to medical treatment as that proposed in Consultation Paper No.128. That is, that no order should be made unless it would bring the incapacitated person greater benefit than making no order at all.[15] Therefore we provisionally propose that:

> **2. The judicial forum must be satisfied that the making of an order will bring greater benefit to the incapacitated person than making no order at all.**

4.10 We consider that the judicial forum should apply the same test as other decision-makers. Whether a particular course of action is in accordance with a responsible body of medical opinion and the opinions of those proposing to treat would be important

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[14] In the United States, the President's Commission has noted that an accessible and informal system might become excessively burdensome if it leads to routine review of an ever larger number and wider range of medical decisions, *Deciding to Forego Life-sustaining Treatment* (1983), p.165.

[15] Consultation Paper No.128, para. 4.12.

factors, but the judicial forum would be required to decide what in all the circumstances was in the incapacitated person's best interests. We provisionally propose that:

3. Any order made should be in the best interests of the incapacitated person, taking into account:

(1) the ascertainable past and present wishes and feelings (considered in the light of his or her understanding at the time) of the incapacitated person;

(2) whether there is an alternative to the proposed treatment, and in particular whether there is an alternative which is more conservative or which is less intrusive or restrictive;

(3) the factors which the incapacitated person might be expected to consider if able to do so, including the likely effect of the treatment on the person's life expectancy, health, happiness, freedom and dignity, but not the interests of other people except to the extent that they have a bearing on the incapacitated person's individual interests.

4.11 Since 1983, England "probably alone among modern developed legal systems"[16] does not provide a legal mechanism by which a guardian may be appointed with authority to consent to the medical treatment of an incapacitated adult.[17] Such a mechanism would allow the appointment of a relative, or friend or a professional to make treatment decisions.[18] However, in countries which already have developed guardianship systems, it has been recognised that it would not be possible for a

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[16] A. Ward, "Tutors to Adults: Developments", [1992] S.L.T. News 325, p.327.

[17] See Consultation Paper No.119, paras. 3.25-3.26.

[18] See M. Gunn, "Treatment and Mental Handicap", Anglo-American Law Review [1987] 242, pp.264-267.

guardian to be appointed to give consent whenever the medical treatment of an incapacitated patient is required.[19] In Alberta, it has been said that guardianship proceedings under the Dependent Adults Act 1980 are costly, time-consuming, and emotionally traumatic for all concerned and should be a last resort.[20] In Victoria, guidelines say that a guardianship application should be made when there is a dispute and all reasonable attempts to resolve it have failed, and where a proposed treatment involves a significant risk or is ethically contentious.[21] In accordance with the principal of minimum intervention, we consider that it would be preferable to deal with specific disputes or treatments with a limited order dealing with the specific issue which has arisen, and to appoint a continuing proxy decision-maker only where this will bring greater benefit to the incapacitated person. We provisionally propose that:

4. An order dealing with a specific issue is to be preferred to the appointment of a proxy, unless there is a need for a continuing authority, and any order should be as limited in scope as possible.

A range of orders

4.12 The Scottish Law Commission has proposed that, on the application of any person having an interest in the welfare of an incapacitated person, a court (or other body set up to deal with such applications) should have power to make orders authorising or prohibiting proposed medical treatment.[22] We consider that similar orders would be useful, but we consider that orders should be concerned with the judicial forum's "approval" rather than "authorisation". Only in the most serious or contentious cases will judicial approval be required,[23] and the usual authority for the

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[19] K. Rosser, "Medical Consent - Legislate or Leave Alone?" (1989) unpublished paper, p.10.

[20] Alberta LRI, Report for Discussion No.11, pp.17-18.

[21] Guardianship and Administration Board Guidelines, *Incapacity and Consent for Health Care* (1990).

[22] Discussion Paper No.94, para. 3.29.

[23] See Part VI below.

treatment will be the statutory authority proposed in Part III of this paper. Therefore we provisionally propose that:

5. The judicial forum may make an order giving or withholding approval to the giving, withholding or withdrawal of particular medical treatment in respect of an incapacitated person.

4.13 We invite views on whether the judicial forum should be able to make recommendations instead of, or as well as, making an order. This was proposed in Consultation Paper No.128[24] and might be useful in the medical treatment context. We provisionally propose that:

6. The judicial forum may make recommendations instead of, or as well as, making an order.

4.14 It has been said that it would be an abuse of a court's powers to order a doctor to carry out a particular treatment.[25] We do not propose that the judicial forum should have such a power. However, it might sometimes be appropriate for a different professional, who is prepared to offer a particular treatment, to take over responsibility for the patient. The judicial forum might have the power to order this where, for example, there is uncertainty or a dispute about whether the treatment offered is appropriate. We provisionally propose that:

7. The judicial forum may make an order requiring the person or persons responsible for the medical care of an incapacitated person to allow some other person, who agrees to take over the care of the incapacitated person, to do so.

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[24] Paragraph 6.15.

[25] *Re W* [1992] 3 W.L.R. 758, 769 *per* Lord Donaldson M.R.

A declaratory jurisdiction

4.15 In addition to the jurisdiction to approve treatment on the incapacitated patient's behalf we consider that the judicial forum should have a *declaratory* jurisdiction. This would not be concerned with making decisions on behalf of the incapacitated person, but with establishing and declaring the existing state of affairs.

4.16 Reference to the judicial forum might occur where a patient's capacity is in question. If the person is found not to be incapacitated then there should be power to make a declaration to that effect. We provisionally propose that:

> **8. The judicial forum may declare that the person concerned is or is not incapacitated, either in general or in relation to a particular matter.**

4.17 We consider that a declaration would also be the most appropriate way to deal with questions of the scope or validity of the patient's own decisions. If the person is now incapacitated, and has made no valid decision which is applicable to the situation which has arisen, the forum would be able to make a decision on the person's behalf[26] if it would benefit the incapacitated person to do so.[27] We provisionally propose that:

> **9. The judicial forum may make a declaration as to whether or not an apparent decision by the patient concerned is "clearly established" and "applicable in the circumstances".**

4.18 A patient with the capacity to do so may make a decision which is contrary to his best interests "on any objective view".[28] It would not be appropriate for a person to be declared to have the capacity to make his own decisions, or for his decision to be declared to be "clearly established" and "applicable to the circumstances" which have

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[26] See para. 4.10-4.12 above.

[27] See para. 4.9 above.

[28] *Airedale NHS Trust* v. *Bland* [1993] 3 W.L.R. 316, 393 *per* Lord Mustill.

arisen, only where the declaration would benefit the person concerned. If the person has the capacity to decide, then his right to take his own decision should be preserved, however unfortunate the consequences of his decision might appear. Nevertheless, we consider that judicial confirmation of the decision of every patient who refuses treatment would be inappropriate. Under the current law, Lord Donaldson M.R. has said that a declaration should be sought where there are "real doubts" as to the effect of a purported refusal of treatment, where failure to treat threatens the patient's life or threatens irreparable damage to his health.[29] We consider that a similar approach should be adopted to applications to the judicial forum. We invite comment on whether this should take the form of a restriction on the statutory jurisdiction, or should be left to the discretion of the judicial forum.

4.19 In Part VI, we invite views on another use for a declaratory jurisdiction in cases where judicial involvement is required, but it is more appropriate to declare that a proposed step is lawful, than to give approval to it.[30]

Appointment of medical treatment proxies

4.20 We consider that similar provisions might apply to medical treatment proxies as to personal managers under the system proposed in Part VI of Consultation Paper No.128. Accordingly, we provisionally propose that:

> **10. If the judicial forum finds that a single issue order will not be sufficient to benefit the incapacitated person, it may appoint any suitable person who agrees to discharge the duties of a medical treatment proxy for that person. The proxy will have such powers in relation to that person's medical treatment as are specified in the order making the appointment.**

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[29] He considered that such cases would be rare, *Re T* [1992] 3 W.L.R. 782, 798-799.

[30] See paras. 6.23-6.24 and 6.29 below.

In most cases the powers specified will be the authority to give or refuse consent to medical treatment, or to particular types of medical treatment. We invite views on whether there are other powers which a medical treatment proxy might be granted. A person proposing to provide a treatment, in relation to which a proxy has been granted authority to give or refuse consent, would be under a duty to obtain the proxy's consent rather than to consult the incapacitated person's "nearest relative".[31] We provisionally propose that:

> **11. If a medical treatment proxy has been appointed, a person proposing to provide treatment which is within the scope of the proxy's authority should be under a duty to obtain the proxy's consent, or the approval of the judicial forum, before that treatment is given. There should be no duty to consult the incapacitated person's "nearest relative" in relation to treatments within the authority of the proxy.**

4.21 We have provisionally proposed that the appointment of a Director of Social Services as a personal manager should be possible as a last resort.[32] In relation to medical treatment proxies, we are not persuaded that there is a need for similar appointments. If a person who knows the incapacitated person well is not available, it is unlikely that the involvement of another professional will add to the medical team's knowledge of the person. We invite comments on this.

4.22 It might be useful to appoint proxies to act jointly, or jointly and severally. In most cases the effect of a dispute between joint proxies would be to allow the treatment provider to proceed on the basis of the statutory authority. However, it would be possible for the judicial forum to make an order at the same time as the appointment, prohibiting particular treatments unless both proxies were in agreement or the matter

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[31] See paras. 3.62-3.65 above.

[32] Consultation Paper No.128, para. 6.19.

was referred back to the judicial forum. As in Consultation Paper No.128 we doubt the need for successive or alternate appointments,[33] but we provisionally propose that:

12. The judicial forum may appoint joint, joint and several, alternate or successive medical treatment proxies.

4.23 We invited comment on a duration of six or twelve months for personal orders and the appointments of personal managers.[34] The same time limits might be appropriate in relation to medical treatment. We provisionally propose that:

13. The maximum duration of any order or appointment by the judicial forum should be [six or] twelve months in the first instance. Appointments should be renewable for [six or] twelve months at a time.

4.24 We do not consider that there is a need for a supervisory body, such as the Mental Health Act Commission, in relation to those for whom a medical treatment proxy has been appointed.[35] We invite comment on this.

4.25 We consider that a proxy should take into account the same factors as others involved in making medical treatment decisions on behalf of an incapacitated person. In Consultation Paper No.128, we proposed that a personal manager should be under a positive duty to take action in the incapacitated person's best interests. Since a proxy will have been appointed because the judicial forum considers that this will benefit the incapacitated person, and the proxy will have consented to his appointment, it seems reasonable to impose the same duty on a medical treatment proxy. We provisionally propose that:

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[33] Paragraph 6.20.

[34] Consultation Paper No.128, paras. 6.22-6.23.

[35] This is proposed in relation to personal managers in Consultation Paper No.128, paras. 6.24-6.25.

14. A medical treatment proxy must act in the best interests of the incapacitated person, taking into account:

(1) the ascertainable past and present wishes and feelings (considered in the light of his or her understanding at the time) of the incapacitated person;

(2) whether there is an alternative to the proposed treatment, and in particular whether there is an alternative which is more conservative or which is less intrusive or restrictive;

(3) the factors which the incapacitated person might be expected to consider if able to do so, including the likely effect of the treatment on the person's life expectancy, health, happiness, freedom and dignity, but not the interests of other people except to the extent that they have a bearing on the incapacitated person's individual interests.

4.26 We consider that reimbursement of the expenses of a medical treatment proxy should be permitted from the estate (if any) of the incapacitated person.[36] We provisionally propose that:

15. A medical treatment proxy should be able to recover the expenses of acting.

Access to medical records

4.27 Under the Access to Health Records Act 1990, where a patient is "incapable of managing his own affairs", any person appointed by a court to manage those affairs

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[36] This is proposed in relation to personal managers in Consultation Paper No.128, para. 6.31.

may apply for access to the patient's health care records.[37] Therefore, under the current law, a receiver appointed by the Court of Protection in relation to the incapacitated person's financial affairs can make an application. We consider that a medical treatment proxy should have the right to make an application for access to health care records under this legislation,[38] and under the Data Protection Act 1984.[39] We therefore provisionally propose that:

16. A medical treatment proxy should be able to exercise the rights of the incapacitated person to apply for access to health records under the Access to Health Care Records Act 1990 and the Data Protection Act 1984, unless this possibility is specifically excluded by the judicial forum.

Limitations on the authority of a medical treatment proxy

4.28 Most of the reasons for limiting the treatment provider's authority to proceed without the consent of the patient[40] will still operate even if the consent of the proxy has been obtained. Similarly, if an anticipatory refusal of pain relief and "basic care" should be regarded as ineffective[41] so should a similar proxy refusal. Therefore we provisionally propose that:

17. A medical treatment proxy should have no authority to refuse pain relief or "basic care", including nursing care and spoon-feeding.

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[37] Section 3(1)(e).

[38] In Scotland, the power to exercise rights under the Access to Health Care Records Act 1990 is customarily included in the powers conferred on a tutor-dative. See G. Ashton and A. Ward, *Mental Handicap and the Law* (1992), p.146.

[39] Health records which are available under s.21 of the Data Protection Act 1984 are excluded from the scope of the Access to Health Records Act 1990. Section 21(9) of the Data Protection Act 1984 contemplates that provision may be made for requests to be made on behalf of an individual who is "incapable by reason of mental disorder of managing his own affairs".

[40] Paragraphs 3.41-3.45 above.

[41] See paras. 3.22-3.26 above.

18. **A medical treatment proxy should have no authority to consent to the carrying out of any treatment contrary to a valid anticipatory refusal by the person who is now incapacitated, or a prohibition by the judicial forum.**

19. **A medical treatment proxy should have no authority to consent to the taking of any step for which the approval of the judicial forum or some other person is required (see Part VI).**

4.29 Except in an emergency, the involvement of the judicial forum will be necessary where the patient objects to a proposed treatment. However it may sometimes be appropriate for the judicial forum to appoint a proxy with the authority to consent to treatment in such circumstances.[42] The treatment provider would still have to assess the person's capacity to give or refuse consent and the proxy's authority would operate only where the person was found to be incapacitated in relation to the treatment decision in question. We consider that an authority to consent to treatment to which the incapacitated person objects should have to be granted explicitly. We therefore provisionally propose that:

20. **A medical treatment proxy should have no authority, unless granted explicitly by the judicial forum, to consent to the carrying out of any treatment to which the incapacitated person objects.**

Applicants

4.30 We consider that those close to the incapacitated person should be able to seek an order. This would include close relatives,[43] people with whom the person has

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[42] See para. 4.32 below.

[43] This might be defined as the first four people from the list of relatives for the purpose of the Mental Health Act 1983, s.26.

ordinarily resided,[44] and (if appointed) a medical treatment proxy or attorney or a personal welfare manager or attorney. A person who is regarded as incapacitated should be able to seek an order, including a declaration that he is not incapacitated. Health authorities and individual professionals responsible for a patient's care should also be able to apply for orders. Other people would be able to seek leave to make an application. We provisionally propose that:

21. **Close relatives, people with whom the incapacitated person has resided, medical treatment proxies or attorneys, personal welfare managers or attorneys, and the person himself or herself, should have a right to apply for an order. The health authority or any person responsible for the incapacitated person's health care should also have a right to apply. Other persons might apply with leave of the judicial forum.**

The authorisation of treatment to which the incapacitated person objects

4.31 We consider that the system outlined in this Part would provide a framework for the authorisation of treatment to which an incapacitated person objects. Where an application is made the judicial forum would have to establish whether the person is incapacitated.[45] Even if the person is found to be incapacitated, no order would be made unless it is established that this would bring greater benefit to the incapacitated person than making no order. Any order would have to be in the best interests of the incapacitated person, after consideration of the appropriate factors, in particular the views of the person and the existence of any less restrictive alternative treatments.[46] We invite views on whether any additional procedures or criteria should be included.

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[44] Some qualifying time period might be included, although five years, which is required for qualification as a "nearest relative" under the Mental Health Act 1983, s.26(7), might be too long.

[45] If the patient is found not to be incapacitated, it may be appropriate to make a declaration to that effect, para. 4.16 above.

[46] Paragraph 4.10 above.

4.32 In New South Wales, the Disability and Guardianship Act 1987, s.33(3), provides that where the patient objects only the Guardianship Board may consent unless there is an emergency. It has been said that this provision causes problems because of the large number of incapacitated people who regularly resist treatment because they lack understanding, but for whom it would be impractical to make an application on every occasion.[47] Although the Board might be able to give a continuing consent, it was suggested that it would be more practical to allow guardians to consent despite the patient's objections.[48] We have proposed that it should be possible for a medical treatment proxy to have authority to consent in these circumstances.[49]

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[47] K. Rosser, "Medical Consent - Legislate or Leave Alone?" (1989) unpublished paper, p.20.

[48] *Ibid.*, p.20.

[49] Paragraph 4.29 above.

PART V

ENDURING POWERS OF ATTORNEY

5.1 The Scottish Law Commission has proposed that it should be possible to appoint an attorney with power to consent and withhold consent to medical treatment and to require treatment to be discontinued.[1] However it was considered that binding directions either by the patient or his attorney downgrades the status of doctors, because their "professional judgments and contributions are ignored and they become mere technicians carrying out the directions of attorneys". Therefore it was said that doctors should only be required to give due weight to the views expressed and should not be bound by them.[2]

5.2 We do not consider that the requirement to obtain the consent of a patient with the capacity to give it downgrades the doctor's status or reduces him to a mere technician and we have difficulty seeing how the situation would be significantly different where the consent is sought of an attorney acting on the person's behalf. A person with the authority to consent is not a "sole decision-maker" because, as Lord Donaldson has pointed out, no one can dictate the treatment to be given. Doctors can recommend one treatment in preference to another, while refusing to adopt some other treatment. The person who is authorised to consent can refuse to consent to any treatment offered, but cannot insist on the treatment which the doctor is not prepared to administer. The inevitable and desirable result, said Lord Donaldson M.R., is that a choice of treatment is in some measure a joint decision of the doctors and the person authorised to consent.[3]

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1 Scottish Law Commission Discussion Paper No.94, para. 5.109.

2 *Ibid.*, para. 5.116.

3 *Re J* [1991] Fam. 33, 41.

5.3 Medical treatment attorneys may be appointed in a number of American[4] and Australian[5] States and Canadian provinces[6] and have been proposed in a number of others.[7] Significant support for their introduction has been reported amongst one group of patients,[8] and there was considerable support for their introduction amongst the respondents to Consultation Paper No.119. We consider that an attorney should be able to consent to or refuse treatment on an incapacitated person's behalf if he has been appointed for that purpose. We provisionally propose that:

1. **It should be possible for a person to execute an enduring power of attorney giving another person the authority to give or refuse consent on his or her behalf to some or all medical treatment in relation to which the donor has become incapacitated.**

5.4 We consider that, as far as possible, similar provisions should apply to the appointment of medical treatment attorneys as to appointing a person to make personal welfare and financial decisions.[9]

Procedures and Safeguards

The effect of incapacity

5.5 Enduring powers of attorney made under the current law in relation to "property and affairs" may be, and usually are, effective from the date of execution.[10] In

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4 Thirty States have "durable power of attorney for health care" legislation, C. Schlyter, *Advance Directives and AIDS* (1992), p.58.

5 Victoria, Medical Treatment (Enduring Power of Attorney) Act 1990, amending the Medical Treatment Act 1988.

6 Nova Scotia, Medical Consent Act 1988, s.1; Quebec, Civil Code, art.1731.1; Ontario, Substitute Decisions Act 1992, s.46(8).

7 For example Manitoba LRC, Report No.74; Alberta LRI, Report for Discussion No.11; Newfoundland LRC, WP6.

8 See para. 3.66 above.

9 See Consultation Paper No.128, paras. 7.4-7.38.

10 See Consultation Paper No.128, para. 7.5.

Consultation Paper No.128 we provisionally proposed that the authority of a personal care attorney should not depend upon the absence of capacity on the part of the donor, since such a stipulation would impose a heavy burden of assessment on the attorney.[11] There are different considerations in relation to medical treatment where there is already an obligation to assess the patient's capacity to give consent before carrying out any treatment. If the person is found to have the capacity to make his own decision, there would be no reason to involve the attorney. Therefore we provisionally propose that:

2. **The authority of an attorney in relation to a particular medical treatment decision should operate only where the donor is incapacitated in relation to that decision according to the definition of incapacity proposed in Part II of this paper.**

5.6 It follows from this proposal that the donor might have capacity to make certain decisions, at the same time as the attorney has authority to make others in relation to which the donor is incapacitated. It is also possible that a person might be incapacitated in relation to a treatment decision but will have the capacity to appoint a medical treatment attorney to make the decision on his behalf, or to revoke an existing power. Since the giving and revoking of a power is a legal transaction and not a decision about whether to accept or reject medical treatment the test of capacity for this purpose should be that proposed in Part III of Consultation Paper No.128.[12] We provisionally propose that:

3. **A donor under a medical treatment EPA should always retain the power to do any act, including revoking the EPA, in relation to which he or she has capacity at the time. The definition of incapacity for the purpose of the execution or revocation of a medical treatment EPA should be the same as that proposed in Part III of Consultation Paper No.128.**

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[11] Paragraph 7.9.

[12] The same test was put forward for consultation as the test proposed in Part II of this paper. However, it might be decided that the tests should be different.

A standard form

5.7 The working party which produced the *Living Will* report proposed that a prescribed form was desirable for the making of anticipatory decisions. This was not thought necessary for "durable powers of attorney for health care", but it was said that there might be a case for requiring explanatory notes to be included.[13] Partly because of the wide range of possible forms and content we have not proposed a prescribed form for anticipatory decision-making,[14] but there would be less difficulty with requiring the use of a standard form for the appointment of a medical treatment attorney. Attorneys will be in a position of considerable responsibility and an appropriate standard form might ensure that the donor understands the possible consequences of the appointment. A standard form might list particular treatments or situations in relation to which the donor must decide whether the attorney is to have authority.[15] For example, an attorney should not have authority to consent to treatment for mental disorder,[16] or involvement in medical research,[17] unless such authority were granted explicitly. Refusal of life-saving treatment, either in general or in relation to particular situations such as terminal illness, would be another example. We invite views on the content of a standard form.

Execution requirements

5.8 Confirmation of the donor's capacity at the time of execution might be a useful safeguard. Certification of this by a solicitor and a registered medical practitioner was

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[13] *The Living Will* (1988), p.72.

[14] Paragraphs 3.14-3.17 above.

[15] In Consultation Paper No.128, para. 7.13, we invited views on whether a standard form for the appointed of a personal welfare attorney should list a range of powers which the donor can choose whether to delegate and require the donor positively to choose which ones to delegate.

[16] This is considered in Part VII below.

[17] Medical research is considered at paras. 6.14 and 6.26-6.29 below.

suggested in Consultation Paper No.128.[18] We invite comments on a similar procedure for medical treatment powers. We provisionally propose that:

4. **The donor's capacity to execute a medical treatment EPA should be certified by a solicitor and a registered medical practitioner at the time of execution.**

Notification requirements

5.9 In Consultation Paper No.128 we proposed that a donor should name at least two people who should be notified of the execution of the power, and whose acknowledgement is required before the attorney is permitted to act.[19] It may be that such a requirement would be cumbersome in the context of medical treatment powers. Notification which does not take place until the donor becomes incapacitated might take too long. The donor may become incapacitated suddenly, in an accident for example, and treatment decisions might have to be made urgently. A requirement of notification at the time of execution might require the donor to reveal information which he prefers to keep private. Nevertheless, notification might be a useful safeguard and we provisionally propose that:

5. **A donor should name in a medical treatment EPA the two (or more) persons who are to be notified of its execution and no action should be taken by an attorney under the power unless and until an acknowledgement has been received from the persons so named.**

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[18] Paragraph 7.15.

[19] Paragraph 7.17-7.18.

Assessment by prior appointees

5.10 The donor might wish the attorney's authority to depend upon an independent finding of incapacity, or some other event, and we see no reason why the power should not contain a requirement to this effect. Therefore we provisionally propose that:

6. The donor should be permitted to name someone to confirm his or her incapacity, or to establish any other ground upon which the authority of the attorney depends.

Registration

5.11 In Consultation Paper No.128 we proposed that there should be no requirement that financial or personal powers should be registered when the attorney believes the donor is or is becoming incapacitated. We can see no greater justification for such a requirement in the context of medical treatment powers. Therefore we provisionally propose that:

7. There should be no requirement that a medical treatment EPA be registered with the Court of Protection, or any other authority, when the attorney believes the donor to be or be becoming incapacitated.

Attorneys

5.12 As with attorneys for personal care,[20] we consider that medical treatment attorneys should be individuals. We provisionally propose that:

8. Only individuals should be capable of being appointed medical treatment attorneys.

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[20] Consultation Paper No.128, para. 7.24.

5.13 It might be valuable to appoint more than one attorney, either as a safeguard so that one may be a check on the other, or so that an attorney is more likely to be available if a decision is required urgently. Disagreement between joint attorneys would result in a failure to either give or refuse consent to the treatment in question so that the treatment could be provided in accordance with the statutory authority.[21] Where joint and several attorneys disagree, and the power does not provide for priority between them, the treatment provider would be entitled to rely on the consent of one. In either case the dispute could be referred to the judicial forum. We considered that it should be possible to appoint alternate personal or financial attorneys,[22] and we consider that it should be possible to appoint alternate medical treatment attorneys also. We provisionally propose that:

9. It should be possible for more than one person to be appointed as medical treatment attorneys, whether to act jointly or jointly and severally. It should also be possible for alternate attorneys to be appointed to act in the event of original attorneys ceasing to act.

5.14 We do not consider that there would be any value in being able to appoint any public official in an official capacity as a treatment attorney. Such a person would not be able to contribute any knowledge of the incapacitated person's circumstances or values to the considerations of the medical team. We therefore provisionally propose that:

10. It should not be possible to appoint public officials in their official capacity as medical treatment attorneys.

5.15 We invite views on whether there should be any other restrictions on appointment as a medical treatment attorney.

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[21] Paragraph 3.40 above.

[22] Consultation Paper No.128, para. 7.25.

5.16 We do not propose that a duty to act should be imposed on medical treatment attorneys by statute. If an attorney chooses to give or refuse consent on the donor's behalf we consider that there should be a duty to do so in the donor's best interests considering the same factors as other people involved in the decision. Although the BMA has suggested that the person appointed should apply a substituted judgment approach, acting as a sympathetic interpreter of the patient's own values, rather than attempting to judge the patient's best interests,[23] we prefer to treat the patient's values as a factor to be considered when deciding what his best interests require. The attorney and the treatment provider will have different contributions to make to the decision, based upon their knowledge of different aspects of the person concerned, but we do not see an advantage to requiring each to apply a different standard.[24] Therefore we provisionally propose that:

11. A medical treatment attorney should be under no duty to express a view on behalf of the donor. If an attorney chooses to give or refuse consent to a particular medical treatment, he or she must do so in the best interests of the incapacitated person, taking into account:

(1) the ascertainable past and present wishes and feelings (considered in the light of his or her understanding at the time) of the incapacitated person;

(2) whether there is an alternative to the proposed treatment, and in particular whether there is an alternative which is more conservative or which is less intrusive or restrictive;

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[23] *Statement on Advance Directives* (1992), p.3.

[24] A more recent statement from the BMA and the Royal College of Nursing, says that, if the patient cannot express a view, "the opinion of family or others close to the patient may be sought regarding the patient's best interests", *Decision relating to cardiopulmonary resuscitation* (1993), p.3.

(3) the factors which the incapacitated person might be expected to consider if able to do so, including the likely effect of the treatment on the person's life expectancy, health, happiness, freedom and dignity, but not the interests of other people except to the extent that they have a bearing on the incapacitated person's individual interests.

5.17 We do not consider that it is necessary to require the attorney to consult any other person who may have been appointed attorney or manager, in relation to the incapacitated person's financial or personal affairs. Nevertheless we invite views on this.

5.18 A person proposing to provide a treatment in relation to which a medical treatment attorney has been granted authority to give or refuse consent would be under a duty to consult with the attorney, and to give the attorney the opportunity to give or refuse consent. There would be no duty to consult the incapacitated person's "nearest relative". We provisionally propose that:

12. If a medical treatment attorney has been appointed, a person proposing to provide a treatment within the scope of the attorney's authority should be under a duty to give the attorney the opportunity to give or refuse consent on the incapacitated person's behalf. There should be no duty to consult the incapacitated person's "nearest relative" in relation to treatments within the scope of the attorney's authority.

Access to medical records

5.19 We consider that a medical treatment attorney should have the right to make an application for access to the incapacitated person's health care records under the Access to Health Care Records Act 1990 and under the Data Protection Act 1984, unless the

donor specifically excludes this from the powers which the attorney is to have. We therefore provisionally propose that:

13. A medical treatment attorney should be able to exercise the rights of the incapacitated person to apply for access to health records under the Access to Health Care Records Act 1990 and the Data Protection Act 1984, unless this possibility is specifically excluded in the power.

Limitations on the authority of an attorney

5.20 We consider that similar restrictions should apply to the authority of medical treatment attorneys as those proposed in relation to medical treatment proxies appointed by the judicial forum.[25] Therefore we provisionally propose that:

14. A medical treatment attorney should have no authority to refuse pain relief or "basic care", including nursing care and spoon-feeding.

15. A medical treatment attorney should have no authority to consent to the carrying out of any treatment contrary to a prohibition by the judicial forum, or, unless the power provides otherwise, a valid anticipatory refusal by the donor.

16. A medical treatment attorney should have no authority to consent to the taking of any step for which the approval of the judicial forum or some other person is required (see Part VI).

17. A medical treatment attorney should have no authority to consent to the carrying out of any treatment to which the incapacitated person objects.

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[25] Paragraphs 4.28-4.29 above.

The powers of the judicial forum

5.21 In Consultation Paper No.128, we proposed that the judicial forum should have wide powers to give effect to the intentions of the donor of an EPA for financial affairs or personal care.[26] We invite comment on whether such powers might also be valuable in relation to medical treatment EPAs. We provisionally propose that:

> **18. The judicial forum should have power to give effect to the wishes of the donor by curing technical defects in the appointment of a medical treatment attorney, or by appointing a replacement for an attorney who is unable or unwilling to act, and, provided that the donor has so directed, by modifying or extending the scope of the powers granted.**

Supervision and review of medical treatment EPAs

5.22 The BMA has said that decisions made by a person nominated by the patient have a "significant determinative value" but that it should be possible to challenge, and if necessary displace, a substitute decision-maker whose actions are "mischievous".[27] In the Alberta proposals any interested person may apply to the court to have the decision of an attorney reviewed, and the attorney's authority may be rescinded if the decision is "unreasonable" having regard to the decision-making criteria.[28] In the Manitoba and Newfoundland proposals it is necessary for the court to be satisfied that an attorney is acting in bad faith or contrary to the known wishes of the patient[29] and in Newfoundland there is an additional ground where the attorney's interpretation of the patient's wishes does not have any "rational foundation".[30] These grounds restrict a

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[26] Paragraphs 7.35-7.37.

[27] *Statement on Advance Directives* (1992), p.3.

[28] Alberta LRI, Report for Discussion No.11, pp.74-75.

[29] Manitoba LRC, Report No.77, p.33.

[30] Newfoundland LRC, WP6, p.89.

court's ability to substitute its view for that of the attorney who is assumed to be in the best position to decide for the patient. However, in Victoria, legislation allows any concerned person to apply to the Guardianship and Administration Board if the attorney is not acting in the patient's best interests. We propose that, as in relation to other disputes about an incapacitated patient's medical treatment,[31] the patient's best interests should determine the issue. However in determining whether the proxy is acting in the patient's best interests the patient's views and reasons for choosing the attorney will have to be considered and should be accorded considerable significance. We provisionally propose that:

19. The judicial forum should have wide powers to revoke the appointment of an unsuitable medical treatment attorney, and to substitute its own decision for the decision of a medical treatment attorney who is not acting in the best interests of the incapacitated person.

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[31] See para. 4.10 above.

PART VI

INDEPENDENT SUPERVISION OF CERTAIN DECISIONS

6.1 Lord Brandon in *Re F* said that if the lawfulness of a doctor providing treatment to an adult patient disabled from giving consent required the approval or sanction of a court, the whole process of medical care for such patients would grind to a halt.[1] Most forms of treatment ought to proceed if there is agreement among the professionals involved, the family and other interested individuals, and the patient to the extent that he can express a view. However, it has been argued that certain circumstances should call attention to the need for independent review or other safeguards.[2]

Treatments in a "special category"

6.2 Even in relation to the most serious and controversial treatments, the House of Lords decided in *Re F*, with Lord Griffiths dissenting, that there is no power to require that the approval of a court should be sought before they are carried out upon an incapacitated adult. Nevertheless applications were highly desirable "as a matter of good practice" in certain cases. Under a statutory scheme it would be possible to require the involvement of a judicial, or some other, authority as a matter of law. The Scottish Law Commission has proposed that there should be a category of "exceptional treatments" specified by regulations made by the Secretary of State. Except in an emergency, the carrying out of such a treatment on a "mentally disabled" patient would require the consent of a court.[3] We agree that there may be a category of treatments which justify a similar approach and we consider that there may be decisions to withdraw or withhold certain treatments which should also be included. Therefore we provisionally propose that:

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1 [1990] 2 A.C. 1, 56.

2 L. Gostin in C. Dyer (ed.), *Doctors, Patients and the Law* (1992), p.85.

3 Discussion Paper No.94, paras. 3.25-3.28.

1. **There should be a "special category" of steps which require the approval of the judicial forum before they are taken in relation to an incapacitated person, except where the step is essential to prevent an immediate risk of serious harm to that person.**

The content of the "special category"

6.3 Treatments which should be placed in the special category are likely to be those which have an irreversible impact upon the patient's functioning, and which involve ethical considerations going beyond purely clinical judgments. We consider that additions to the special category might be specified by regulations made by the Secretary of State,[4] but there are a number of treatment decisions which have already raised concern. We wish to consult on whether these should be included in the special category.

(i) Sterilisation operations

6.4 All the speeches in the House of Lords in *Re F* suggested that the involvement of a court was appropriate before a mentally incapacitated woman is operated on in order to prevent conception. Lord Goff referred to the irreversible interference with the right to reproductive autonomy[5] and Lord Brandon to the irreversible deprivation of one of the fundamental rights of a woman, the right to bear children.[6] There was also a risk that such operation would be carried out for improper reasons or with improper motives,[7] for the convenience of those who are charged with the person's care,[8] or as a matter of administrative convenience.[9] Court involvement would provide an

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[4] As under s.57(1)(b) and s.58(1)(b) of the Mental Health Act 1983.

[5] *Re F* [1990] 2 A.C. 1, 78.

[6] [1990] 2 A.C. 1, 56.

[7] *Ibid.*, at p.56 *per* Lord Brandon.

[8] *Ibid.*, at p.69 *per* Lord Griffiths.

[9] *Ibid.*, at p.79 *per* Lord Goff.

independent, objective, and authoritative view on the lawfulness of the procedure, after a hearing with independent representation on behalf of the person upon whom it is proposed to perform the operation,[10] and would protect those concerned with the provision of the treatment from subsequent adverse criticism or claims.[11]

6.5 Special considerations were said to apply because the operation was neither curative nor prophylactic,[12] nor for the treatment of diseased organs,[13] and, in the Court of Appeal, Lord Donaldson distinguished between operations intended to secure sterilisation, and those with that incidental result.[14] In *Re GF (Medical Treatment)*,[15] a hysterectomy was proposed for a 29 year old woman with a severe learning disability whose heavy menstruation was becoming increasingly distressing and disturbing to her. Although this would have the incidental effect of sterilising her, this was said not to be its purpose. In a similar case involving a child,[16] it was said that "this is not a case where the doctors are saying that this young girl should be sterilised because it would be wrong for her to become pregnant". A distinction was made between cases where an operation is required for "genuine therapeutic reasons" and those where the operation is designed to achieve sterilisation. The Scottish Law Commission adopted a similar approach proposing that sterilisation for "therapeutic reasons" would not require court approval.[17]

6.6 We do not consider that an operation to remove a malignant tumour should be included in the special category, even where it has the incidental effect of rendering the

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[10] *Ibid.*, at pp.78-79 *per* Lord Goff.

[11] *Ibid.*, at p.56 *per* Lord Brandon.

[12] *Ibid.*, at p.52 *per* Lord Bridge.

[13] *Ibid.*, at p.69 *per* Lord Griffiths.

[14] *Ibid.*, at p.19.

[15] [1992] 1 F.L.R. 293.

[16] *Re E (A Minor) (Medical Treatment)* [1991] 2 F.L.R. 585.

[17] Discussion Paper No.94, para. 3.28.

person infertile,[18] but a hysterectomy for menstrual management may raise quite different issues. Whatever the intention, the effect is the irreversible deprivation of reproductive capacity. There is also a risk that the operation will be, or will be thought to be, motivated by the convenience of those caring for the incapacitated person. These considerations might suggest that such operations should be included in the same category as contraceptive sterilisation. South Australian legislation includes sterilisation operations for the purpose of the cessation of menstruation as well as contraception in framing criteria for "non-therapeutic" sterilisations.[19]

6.7 However, even where the operation is intended to prevent conception, the need for the involvement of a judicial forum in every case has been questioned. It has been suggested that the dangers of error or abuse may be no greater in relation to sterilisation than other treatments, and that the availability of judicial involvement ought to suffice to protect the patient's interests.[20] Lord Goff has noted a review being undertaken by the President of the Family Division to determine whether the practice of making applications in every case might be relaxed.[21] One of our respondents, with considerable experience of such cases, suggested that all those involved are frequently agreed that there is no alternative to the proposed operation so that a dispute has to be "manufactured" for the purpose of the hearing.

6.8 Nevertheless, there appeared to be continued support for judicial approval of sterilisation from a significant number of our respondents. A more informal and

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[18] But note that, in South Australia, sterilisation is defined as any procedure that results or is likely to result in the person being infertile (Mental Health Act 1977, s.5) and in New South Wales, "special medical treatment" includes any medical treatment that is intended, or is reasonably likely, to have the effect of rendering permanently infertile the person on whom it is carried out (Disability Services and Guardianship Act 1987, s.33). In both cases, the consent of the Guardianship board is required unless the operation is necessary to meet an imminent risk to the patient's life or health.

[19] Mental Health Act 1977, s.28(2)(a)(i)(ii) and (iii)(A) or (B). There is no definition of "therapeutic" and "non-therapeutic". The Australian legislation is discussed in J. Blackwood, "Sterilisation of the Intellectually Disabled: The Need for Legislative Reform", (1991) 5 A.J.F.L. 138.

[20] A. Grubb, in A. Grubb (ed.), *Choices and Decisions in Health Care* (1993), p.50.

[21] *Airedale NHS Trust* v. *Bland* [1993] 2 W.L.R. 316, 376-377.

inquisitorial forum could continue to provide this even if the involvement of the High Court were not required in every case. A hearing could be a more effective safeguard if the judicial forum was required to determine whether, in all the circumstances, sterilisation is in the best interests of the incapacitated person, rather than merely whether it is in accordance with a responsible body of medical opinion.[22] Therefore we provisionally propose that:

2. Sterilisation operations, for the purpose of contraception or menstrual management, should be included in the special category.

Although it would be rare for the sterilisation of an incapacitated man to be in his, rather than another person's, best interests, we consider that such an operation should be included in the special category where it is carried out for contraceptive purposes.

(ii) Donation of tissue

6.9 In *Re F*, Lord Bridge in the House of Lords,[23] and Neill L.J.[24] and Lord Donaldson M.R.[25] in the Court of Appeal, mentioned that an operation to allow *inter vivos* organ donation by an incapacitated adult required similar safeguards to sterilisation. In an American case it was suggested that the donor's "well-being would be jeopardized more severely by the loss of his brother than by the removal of a kidney"[26] but it will be rarely, if ever, that it can be said to be in the best interests of the incapacitated person to donate non-regenerative tissue. We consider that the approval of the judicial forum should be essential before such donation by a mentally incapacitated adult takes place. Similar safeguards might be necessary for the donation of bone marrow. We provisionally propose that:

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[22] Paragraph 4.10 above.

[23] [1990] 2 A.C. 1, 52.

[24] *Ibid.*, at p.33.

[25] *Ibid.*, at p.19.

[26] *Strunk* v. *Strunk* (1969) 445 S.W. 2d 145, 146.

3. **An operation to allow donation of non-regenerative tissue, or bone marrow, should be included in the special category.**

(iii) Abortion

6.10 In the Court of Appeal in *Re F*, Lord Donaldson M.R mentioned abortion along with sterilisation as an operation with an irreversible and emotive character.[27] The medical profession's *Interim Guidelines* included termination of pregnancy among those treatments which the BMA would expect to be the subject of an application to the High Court.[28] However, in *Re SG*[29] the termination of the pregnancy of a 26 year old woman who was severely mentally disabled was recommended as a matter of urgency by a general practitioner and a consultant gynaecologist. Sir Stephen Brown P. said that abortion was outside the category of cases for which a declaration was highly desirable as a matter of good practice. The Abortion Act 1967 was said to provide fully adequate safeguards for the doctors who are to undertake the treatment. Although abortion raised emotive and sensitive issues, the termination of pregnancy was said to be "a very different type of operation" from sterilisation. Be that as it may, as Gillian Douglas has pointed out,[30] the conditions in the 1967 Act are not intended to determine whether the procedure is in the interests of a patient who is unable to make her own decision. However, it has been suggested that the number of cases involved and the urgency with which abortion may be required may make mandatory judicial approval unsuitable in such cases. We simply invite views on whether abortion should be included in the special category.

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[27] [1990] 2 A.C. 1, 19.

[28] Page 3.

[29] *Re SG (Adult Mental Patient: Abortion)* [1991] 2 F.L.R. 329.

[30] [1991] Fam.Law 310.

(iv) Withdrawals of nutrition and hydration

6.11 In relation to the vast majority of patients, a failure to provide nutrition and hydration will be a very serious breach of duty and a crime. However there may be some patients for whom this may not be so, notably those who are in a "persistent vegetative state" with no hope of improvement. Ethically, the BMA has said that medical intervention which cannot benefit a patient in any appreciable way is not justified,[31] and that feeding/gastrostomy tubes for nutrition and hydration should be considered medical treatments for this purpose.[32] Legally, the House of Lords accepted, in *Airedale NHS Trust* v. *Bland*,[33] that it would be lawful to withhold artificial feeding from a patient who obtained no benefit from it.

6.12 The BMA Medical Ethics Committee considered that in cases of persistent vegetative state it would be reasonable to withdraw invasive treatment, including nutrition and hydration, where the clinician judges that there can be no realistic chance of improvement and two other doctors independently concur with that view.[34] However it has been said that, in the interests of the protection of patients and the protection of doctors, and the reassurance of patients' families and the reassurance of the public, an application should be made to a court "as a matter of routine".[35]

6.13 For the same reasons, it seems likely that the withdrawal of nutrition or hydration should be included in the special category. Lord Browne-Wilkinson considered that doctors would be well advised to apply for a declaration in every case for the foreseeable future.[36] However, Lord Goff has suggested that, in future, in view

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[31] BMA, *Euthanasia* (1988), p.10

[32] *Ibid.*, p.23.

[33] [1993] 2 W.L.R. 316.

[34] *Discussion Paper on Treatment of Patients in Persistent Vegetative State* (1992), p.17.

[35] *Airedale NHS Trust* v. *Bland* [1993] 2 W.L.R. 316, 363 *per* Lord Keith, approving the statement of Sir Thomas Bingham M.R. in the Court of Appeal.

[36] *Ibid.*, at p.387.

of the large number of patients who might be the subject of an application, and the cost involved, court involvement may not be needed in every case. This might be restricted to cases where there is a special need for the procedure to be invoked. This might be the case where there was known to be a medical disagreement as to the diagnosis or prognosis, or where "problems had arisen with the patient's relatives - disagreement by the next of kin with the medical recommendation; actual or apparent conflict of interest between the next of kin and the patient; dispute between members of the patient's family; or absence of any next of kin to give their consent."[37] We invite comment on such an approach, but we provisionally propose that:

4. The withdrawal of nutrition or hydration necessary for continuation of the patient's life should be included in the special category.

(v) Medical research

6.14 In their *Interim Guidelines* the BMA said that they would expect certain types of research to be the subject of an application to the High Court.[38] No such application has been made, but there may be some types of research which should be included in the special category.[39] We invite views on this.

(vi) Other decisions

6.15 We invite comment on whether any other treatments or any other decisions to withdraw treatment should be included in the special category.

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[37] *Ibid.*, at pp.376-377.

[38] Page 3.

[39] Local research ethics committees already consider the ethics of research projects involving human subjects but there is no legal obligation to seek approval. Department of Health guidance states that projects which do not have approval of the LREC should not be agreed by any NHS body, NHS Management Executive Guidelines, HSG(91)5.

Criteria for approval

6.16 It would follow from the proposals already made that the judicial forum would not give its approval unless it is satisfied that the person is incapacitated and the decision should not be postponed until capacity is developed or recovered; that he has not made an anticipatory decision rejecting a proposed treatment; and that the proposed course is in his best interests, after consideration has been given to his past and present views and feelings and to whether there are alternatives which are more conservative or less restrictive. Guidance could be developed concerning the type of evidence which the judicial forum would normally require before approval would be granted.[40]

6.17 However the concern which surrounds decisions in the special category might justify the introduction of criteria in addition to, or different from, those normally applied by the judicial forum. These might be applied by other decision-makers for those situations considered above which are not included in the special category.

(i) Sterilisation operations

6.18 It has been argued that non-consensual sterilisation is an unjustifiable violation of human rights if carried out for non-therapeutic reasons[41] and that it denies an aspect of humanity save where it is carried out for exclusively medical reasons.[42] In the Canadian decision *Re Eve*, it was suggested that a court exercising its parens patriae jurisdiction could never safely determine that a sterilisation for a non-therapeutic purpose is in the best interests of a person who is not able to consent to it.[43] In New South Wales, the guardianship board may not consent to a sterilisation operation unless

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[40] As in the Practice Note dealing with sterilisation applications, issued by the Official Solicitor, Practice Note (Official Solicitor: Sterilisation) [1990] N.L.J. 1273. This states that it is anticipated that the judge will expect to receive "comprehensive medical, psychological and social evaluations of the patient from appropriately qualified experts", and indicates what this evidence should establish.

[41] I. Kennedy, *Treat Me Right* (pbk.ed., 1991), p.407.

[42] M. Freeman in M. Freeman (ed.), *Medicine, Ethics and the Law* (1988), p.76.

[43] (1986) 31 D.L.R. (4th) 1.

it is necessary to carry out the treatment in order to save the person's life or to prevent serious damage to the person's health.[44]

6.19 On the other hand it has been said that the effect of *Re Eve* is to send the message that "we insist that you risk having babies" to women for whom other forms of birth control have proved inadequate.[45] The Alberta Institute of Law Research and Reform recommended that the "blanket prohibition" of *Re Eve*, should be replaced by legislation allowing for a judgment based on the best interests of the individual and providing principled guidance for the application of the best interests test.[46] It has also been argued that the New South Wales provision is unnecessarily restrictive and may lead to serious hardship, and that it is "absurdly draconian and excessively protective" to deny a woman a sterilisation operation which is in her best interests merely because she lacks the capacity to consent.[47]

6.20 Clearly it would not be justifiable to perform a sterilisation operation for reasons of eugenics or for the convenience of those caring for the incapacitated person, but we invite views on whether a sterilisation operation should have to be shown to be necessary either to save the person's life or to ensure improvement or prevent deterioration in physical or mental health;[48] or whether it is acceptable to carry out a sterilisation operation on the grounds that it is in the best interests of an incapacitated person whose life would be fuller and more agreeable as a result.[49]

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[44] Disability Services and Guardianship Act 1987, s.45(2).

[45] Alberta Institute of Law Research and Reform, Competence and Human Reproduction (1989), Report No.52, p.37.

[46] *Ibid.*, p.44.

[47] J. Blackwood, "Sterilisation of the Intellectually Disabled", (1991) 5 A.J.F.L. 138, p.166. K. Rosser also argues that this is too rigorous a test and may well lead to hardship for people with disabilities, "Medical Consent - Legislate or Leave Alone?" (1989) unpublished paper, p.21.

[48] See *Re F* [1990] 2 A.C. 1, 55 *per* Lord Brandon.

[49] The basis of the decision in *Re F* according to Lord Keith in *Airedale NHS Trust* v. *Bland* [1993] 2 W.L.R. 316, 361.

(ii) Donation of tissue

6.21 The provisions of the Human Organ Transplant Act 1989 would have to be satisfied before authorisation could be given to the transplantation of an "organ".[50] An offence would be committed under section 2 of the Act unless the donor and recipient were genetically related.[51] We invite views on whether any additional criteria should be established. In the Australian Capital Territory, in addition to being otherwise lawful and in the person's best interests (considering the relationship between the donor and the recipient[52]), non-regenerative tissue transplant or donation may be authorised only if the risk to the person is small; the risk of failure of the transplant is low; the life of the person to whom the organ or tissue is to be transplanted would be in danger if the transplant were not made; and it is highly likely that transplanting the organ or tissue from someone else would be unsuccessful.[53]

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[50] "Organ" means any part of a human body consisting of a structured arrangement of tissues which, if wholly removed, cannot be replicated by the body, s.7(2).

[51] The approval of the Unrelated Live Transplant Regulatory Authority, set up under the Human Organs Transplants (Unrelated Persons) Regulations 1989, S.I. 1989, No.2480, would not be granted unless the donor has consented to the operation. This would not be possible if the donor is incapacitated.

[52] Guardianship and Management of Property Act 1991, s.70(3)(e).

[53] *Ibid.*, s.70(4). The Law Reform Commission of Canada has recommended that:
"Tissue procurement from those persons who are incompetent to consent to donation should be regarded as lawful, when there has been a case-by-case determination by an independent third party (for example, court, review board, ombudsman and so forth) to ensure that the following conditions have been met:
(a) the donation of bone marrow and non-regenerative tissue is restricted to donors and recipients in the same family;
(b) all reasonable, potential procurement and medical treatment alternatives have been exhausted;
(c) the procedure does not involve any serious risk to the donor;
(d) the risk of harms incurred is not disproportionate to the expected benefits;
(e) the legal guardian's consent has been obtained; and
(f) where possible, the potential donor's consent has been obtained, and his or her refusal is always to be respected." Procurement and Transfer of Human Tissues and Organs (1992), Working Paper No.66, pp.174-175. Similar requirements are contained in Council of Europe, "Third Conference of European Health Ministers (Paris, 16-17 November 1987)" (Final Text on Organ Transplantation) (1988) 39 Intl.Dig.Health Leg. 274.

(iii) Abortion

6.22 It would be a precondition for authorisation that an abortion would be lawful under the Abortion Act 1967. We invite views on whether any criteria should be established in addition to those required for the authorisation of other treatments.

(iv) Withdrawals of nutrition and hydration

6.23 There may be a particular problem with such cases, in that sometimes it may not be possible to say that the withdrawal of treatment is in the best interests of the incapacitated person.[54] All that may be said is that it is not in his best interests to continue treatment, and therefore that it is not justifiable to do so. This would continue to be the case under our proposed statutory authority,[55] but the judicial forum would be able to make an order giving approval to withdrawal only where to do so would benefit the incapacitated person[56] and the order made would have to be in the best interests of the incapacitated person.[57] It would follow that no approval could be given to treatment withdrawal in such circumstances.

6.24 However, we tend to consider that the attention which has been focused on patients in persistent vegetative state should not obscure the fact that such patients form a small and atypical part of the population of incapacitated persons. We would not favour distorting our proposals as they apply to the large number of incapacitated people who clearly do have interests, in order to take account of the small number who arguably do not.[58] We consider that a jurisdiction to make declarations that a particular

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[54] "The distressing truth which must not be shirked is that the proposed conduct is not in the best interests of Anthony Bland, for he has no best interests of any kind": *Airedale NHS Trust* v. *Bland* [1993] 2 W.L.R. 316, 398 *per* Lord Mustill.

[55] Paragraph 3.40 above.

[56] Paragraph 4.9 above.

[57] Paragraph 4.10 above.

[58] It is not clear of what proportion of patients in a persistent vegetative state this may be true.

course is lawful might continue to be the appropriate way to provide reassurance to those dealing with these exceptional cases. We invite views on this.

6.25 We also invite views on whether any additional criteria should be established before a declaration is made that it would be lawful not to feed an incapacitated person or approval is given to a decision to withhold or withdraw nutrition or hydration.

(v) Medical research

6.26 A distinction is usually drawn between therapeutic research, where new or alternate methods are tried in order to determine the most effective treatment for a condition, and non-therapeutic research, intended to further medical knowledge rather than to benefit the research subject. The Declaration of Helsinki permits therapeutic research to the extent that it is justified by the potential diagnostic or therapeutic value for the patient.[59] The BMA *Interim Guidelines* suggest that involvement in research may be justified if it is approved by the local research ethics committee, and is expected to produce a direct and significant benefit to the health of the incapacitated person.[60] The principle in *Re F* might authorise treatment which is in the patient's best interests, whether or not there is an element of research involved, and this might also be permitted under the statutory authority proposed in Part III. We invite comment on whether any additional requirements should be satisfied before beneficial treatment is provided which has an additional research objective.

6.27 The lawfulness of non-therapeutic research which involves physical contact with incapacitated subjects is much more doubtful.[61] By definition, it would not be carried out "in order either to save their lives, or to ensure improvement or prevent

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[59] Part II, para. 6.

[60] Page 8.

[61] Guidelines of the Royal College of Psychiatrists stress that many kinds of psychiatric research do not involve physical contact, "Guidelines for Research Ethics Committees on psychiatric research involving human subjects", (1990) 14 Psychiatric Bulletin 48, p.50.

deterioration in their physical or mental health".[62] Even if other factors are considered,[63] it is unlikely that involvement in non-therapeutic research will be in an incapacitated person's best interests.[64]

6.28 It could be argued that non-therapeutic research without consent should not be permitted,[65] but it has been suggested that there is a strong ethical case for non-therapeutic research involving only minimal risk because progress in treatment of people with mental disorders is dependent on better understanding of them.[66] Professional guidelines suggest that non-therapeutic research on incapacitated subjects might be authorised where it benefits persons in the same category as the person and the same scientific results cannot be obtained by research on persons who do not belong to this category;[67] where the incapacitated person does not object to his involvement;[68] and where the risk to the research subject is minimal.[69] Obtaining the agreement of the incapacitated person's close relatives is also suggested.[70]

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[62] *Re F* [1990] 2 A.C. 1, 55 *per* Lord Brandon.

[63] See para. 3.47 above.

[64] The Scottish Law Commission has suggested that a justification could be advanced based on the public interest if the risks are small, and the benefits substantial, Discussion Paper No.94, para. 3.39.

[65] European Commission guidelines on research supporting marketing applications for medicinal products suggest that non-therapeutic studies should not take place without the consent of the subject, Committee of Proprietary Medicinal Products, Note for Guidance, *Good Clinical Practice for Trials on Medicinal Products in the European Community* (1991), para. 1.14. The Scottish Law Commission suggested that this may be an appropriate stance for drug trials but is too restrictive for non-therapeutic research generally, Discussion Paper No.94, para. 3.45.

[66] Royal College of Physicians of London, *Guidelines on the Practice of Ethics Committees in Medical Research Involving Human Subjects* (2nd ed., 1990), para.13.11.

[67] BMA *Interim Guidelines*, p.8.

[68] Royal College of Psychiatrists, *op.cit.*, p.51.

[69] Royal College of Physicians, *op.cit.*, para.13.11

[70] *Ibid.*, para.13.11. The Royal College of Psychiatrists, *op.cit.*, p.51, suggests that close relatives, or an independent person who knows the incapacitated person well and will protect his interests, should attempt to form a judgment as to whether the person would be likely to consent were he able to do so.

6.29 This is another area where the jurisdiction of the judicial forum to approve treatment which is in the best interests of an incapacitated person will be inappropriate,[71] but a declaration could be sought that the research is lawful according to criteria established for this purpose. Such criteria have been tentatively proposed by the Scottish Law Commission.[72] We provisionally propose broadly similar criteria:

5. Non-therapeutic research or experiments on an incapacitated subject should not be lawful unless:

(a) the research is into the mental disorder, or other incapacitating condition, suffered by the subject;

(b) the research entails only an insubstantial foreseeable risk to the subject's physical or mental health. Views are invited on what should constitute an insubstantial risk;

(c) the research has been approved by the appropriate local research ethics committee;

(d) the consent of a medical treatment proxy or attorney appointed with authority to give such consent has been obtained, or (if no such person has been appointed) the subject's nearest relative has agreed in writing;

(e) before seeking such agreement or consent, the purpose of the research, the procedures to be used and the foreseeable risk to participants, have been explained;

(f) the subject does not object to participating in the research, and has made no anticipatory decision refusing to participate.

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[71] See paras. 6.23-6.24 above.

[72] Discussion Paper No.94, para.3.59.

Other safeguards

6.30 There may be some decisions which are outside the special category but for which some independent confirmation is appropriate.

Decisions requiring a "second opinion"

6.31 In *Re GF (Medical Treatment)*,[73] Sir Stephen Brown P. set out criteria which should be satisfied before a hysterectomy should proceed without court involvement. He said that two medical practitioners must be satisfied that the operation is necessary for therapeutic purposes and in the best interests of the patient, and that there is no practicable, less intrusive means of treating the condition. A similar approach might be developed for a range of treatments.

6.32 Professor Brazier has suggested a system for reviewing medical judgments about more serious treatments, using the Mental Health Act 1983 as a model,[74] with long-term medication and major surgery requiring review and authorisation by an independent medical practitioner, while irreversible or controversial surgery might require the authorisation of a doctor appointed by the Mental Health Act Commission.[75] In the BMA *Interim Guidelines* it is said that, for "serious treatments",[76] doctors should seek a second opinion from a doctor skilled in the

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[73] [1992] 1 F.L.R., 293.

[74] *Medicine, Patients and the Law* (2nd ed., 1992), p.104.

[75] *Ibid.*, p.107.

[76] "Any treatment that has one or more of the following characteristics should be regarded as serious:

a any treatment that contemplates an irreversible change in the patient;
b any treatment that is a serious hazard;
c any experimental treatment and all types of research;
d any intervention which as a consequence may shorten the life of the patient;
e any long term regime/intervention designed to effect a change in the mood or behaviour of the patient;
f any treatment, notwithstanding that it does not possess one or more of the above characteristics which should be regarded as serious."

particular treatment proposed and should proceed with the treatment only in exceptional circumstances if the second opinion doctor does not concur.[77]

6.33 We consider that an attempt to identify in legislation all treatments which might be regarded as "serious" would risk being either too vague or too legalistic. However, as in the Mental Health Act 1983, particular treatments requiring a second opinion could be specified in regulations. We invite comment on this approach and the treatments to which it should apply. We provisionally propose that:

5. Certain treatment decisions should require a confirmatory second opinion by an independent registered medical practitioner.

Non-medical opinions

6.34 For some treatments, the approval of some body or person other than a medical practitioner, either as well as or instead of a medical second opinion, might be required. The role of such a body or person would be to ensure that the patient's interests are fully considered, and to refer cases to the judicial forum if the interests of the incapacitated person require this. For treatments to which section 57 applies,[78] the Mental Health Act 1983 provides for certification by two people, who are appointed by the Mental Health Act Commission and are not doctors, that the patient has the capacity to consent. If suitably constituted ethics committees were established, such a committee or a single committee member might be an appropriate authority. The proposals published by the BMA[79] and discussed in Consultation Paper No.119[80] received support from a significant number of respondents. Under these proposals, there would be an ethics committee in each health district. Elective surgery of a simple nature,

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[77] Pages 6-7.

[78] Currently, these are psycho-surgery and the surgical implantation of male hormones for the purpose of reducing male sex drive.

[79] BMA Medical Ethics Committee and Mental Health Committee, *Proposals for the Establishment of a Decision-making Procedure on behalf of the Mentally Incapable* (1991).

[80] Paragraph 6.29.

significant medical decisions relating to long term medication or the use of drugs with major side effects would require the authorisation of a single member of the committee. Any decision about a treatment or procedure which was not simple or straightforward or which had significant side effects[81] would be made by all four members of the committee. We invite views upon this approach, and the treatments to which it should apply. We provisionally propose that:

5. **Certain treatment decisions should require the approval of an independent person or body appointed for this purpose.**

[81] These would include aortography, HIV testing, treatment relating to fertility or pregnancy, major surgical procedures with risk to life, treatment options in patients with terminal illness or any research procedures.

PART VII

TREATMENT FOR MENTAL DISORDER

7.1 In this paper we have provisionally proposed a statutory framework which would authorise the treatment of incapacitated patients and in this part we consider its applicability to treatment for mental disorder. Many mentally disordered people will have the capacity to make their own decisions about treatment. Such patients may be treated without their consent under the Mental Health Act 1983,[1] but they would not be "incapacitated" and so are outside the scope of the scheme proposed in this paper.

7.2 Part IV of the Mental Health Act 1983 is concerned with treatment for mental disorder and it is not our intention to re-open discussion of these provisions.[2] With the exception of section 57, which applies to all patients, Part IV of the Mental Health Act 1983 applies only to those "liable to be detained".[3] Patients admitted to hospital "informally", or those who live in the community, including those subject to guardianship, are not included. It follows that the common law determines the lawfulness of the treatment of such patients, for their mental disorders as well as for other conditions.

The present law

7.3 If the Mental Health Act 1983 provided the only mechanism by which incapacitated patients could receive treatment for their mental disorders, detention in hospital would be necessary whenever treatment was required. The Mental Health Act 1959 began a policy of admitting "non-volitional" patients, that is those who did not

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1 Section 63, which is of course subject to the provisions of s.57 and s.58.

2 See Consultation Paper No.119, para. 1.17.

3 Section 56(1). Certain patients who are "liable to be detained" are also excluded by this section.

object to their admission, on an informal basis[4] and this approach has continued under the current legislation.[5] Such patients may be incapacitated in relation to decisions about their treatment. Patients who live in the community may also be in need of treatment for mental disorder to which they are incapable of consenting. Currently, if such treatment is to be given, its justification must be found in the common law.

7.4 Although *Re F* was not concerned with treatment for mental disorder, it has been argued that it provides a blanket common law justification for treatments for which the statutory provisions, and patient safeguards, of the Mental Health Act 1983 had been considered necessary.[6] The legislation does provide an authority to treat those who are capable of giving or refusing consent, but where the patient is incapacitated the relationship between the common law and the legislation is unclear.

7.5 In *Re F*, in the absence of statutory provision for the giving of the treatment in question, the common law was employed to fill an unjustifiable gap. Where a statutory system is available but has not been employed, a court might be less willing to conclude that necessity or some other common law defence was available.[7] However, in relation to children, treatment for mental disorder has been permitted without detention under the Act and despite the objections of the patient.[8] It has been argued that it may be in the patient's best interests to receive treatment without the stigma which might accompany the use of the legislation. It is unclear to what extent this argument would be accepted where the patient is an adult.

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[4] See the Report of the Royal Commission on the Law relating to Mental Illness and Mental Deficiency 1954-1957 (1957), Cmnd. 169, para. 22.

[5] Mental Health Act 1983, s.131(1).

[6] M. Jones, *Medical Negligence* (1991), p.183.

[7] In the Scottish case of *B* v. *Forsey* [1988] S.L.T. 572, the House of Lords concluded that the powers of detention conferred by the Mental Health (Scotland) Act 1984 were exhaustive and impliedly removed any common law authority to detain which hospital authorities might otherwise have possessed.

[8] *Re R (A Minor) (Wardship: Consent to Treatment)* [1992] Fam. 11; *R.* v. *Kirklees Metropolitan Borough, ex p. C* [1992] 2 F.L.R. 117.

7.6 The Mental Welfare Commission for Scotland has considered this question. The Scottish legislation is very similar to that in England and Wales, and it has been suggested that an interpretation of the common law, similar to that in *Re F*, would probably be upheld.[9] The Mental Welfare Commission was asked whether detention under the Mental Health (Scotland) Act 1984 was necessary in order to treat a patient who was unable to understand the nature, purpose and likely effects of a treatment for mental disorder or whether it would be appropriate to rely on the common law. It was noted that it might be distressing and unnecessarily restrictive for patients living in the community and their relatives if detention were required. The Mental Welfare Commission concluded that:

> "... it would be wise always to seek to detain under the Mental Health Act where treatment for mental disorder is to be given to an incapable patient who is likely to resist the treatment... Where the patient is likely passively to accept the treatment it would appear that the Responsible Medical Officer may either detain the patient under the Mental Health Act or proceed under the common law. In the latter case good medical practice requires a medical second opinion and consultation with those involved in the care of the patient, including relatives."[10]

The proposed statutory scheme

7.7 In principle we consider that the scheme proposed in this paper should apply in those situations where incapacitated patients would now be treated under the common law, including where they are treated for mental disorder. Therefore we provisionally propose that:

> **1. The proposals in this paper should apply to treatment for mental disorder.**

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[9] Scottish Law Commission, Discussion Paper No.94, para. 3.8.

[10] Mental Welfare Commission for Scotland, *Annual Report 1991* (1992), pp.38-39.

7.8 Formal procedures would not be necessary to authorise treatment to which the incapacitated person does not object. The judicial forum would be able to override the objections of an incapacitated patient but we would expect that the usual response to objections to treatment for mental disorder would be to employ the powers available to professionals under the existing legislation.[11]

7.9 In the areas to which it applies, the Mental Health Act 1983 would take precedence over any new scheme, as it does over the common law now. A patient with the capacity to do so would be able to make an anticipatory decision which is applicable to the treatment for mental disorder which he is to receive when incapacitated. However, just as the decisions of a capable patient may be overridden under the Act, an anticipatory decision to refuse treatment for mental disorder would not be binding once the patient is detained. Similarly, if a medical treatment attorney or proxy has been appointed with authority to refuse treatment for mental disorder on the patient's behalf, this authority would be subject to the provisions of the Act permitting treatment to be given without consent.

7.10 Where Part IV of the Mental Health Act 1983 applies we consider that the scheme proposed in this paper should not operate to provide a parallel authority for treatment for mental disorder but would still authorise treatment for other conditions. Therefore we provisionally propose that:

> 2. **The proposals in this paper should not operate in relation to the treatment for mental disorder of an incapacitated person who is subject to Part IV of the Mental Health Act 1983.**

7.11 We invite views on whether some of the safeguards outlined in Part VI above should be applied to particular treatments for mental disorder. The provision of certain

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[11] A review of the legislation is considering whether new legal powers are needed to ensure that mentally ill people in the community receive care which they need (Mrs. Virginia Bottomley, Written Answer, *Hansard* (H.C.), 13 January 1993, vol.216, col.731). There would be no question of avoiding the limitations of the legislation by seeking authorisation from the judicial forum. The protections provided for the incapacitated person would be at least as effective as those provided under the Act.

treatments might require a second opinion,[12] perhaps certifying that the patient was incapacitated and did not object to the proposed treatment, and that having regard to its alleviating or preventing a deterioration of his condition, it should be given. This could amount to extending the extra safeguards applied to the administration of medicine for three months[13] or electro-convulsive therapy[14] applicable to detained patients to include incapacitated informal patients.

7.12 We also invite views on whether these or any other treatments for mental disorder should be excluded from the authority of attorneys or proxies.[15] An attorney under the Californian Durable Power of Attorney Act 1983 may not consent to psychosurgery,[16] but it has been suggested that it is unlikely that there is any justification for such an exclusion here.[17] Nevertheless the authority to provide such treatment to an incapacitated person would be limited by the provisions of section 57 of the Mental Health Act 1983. This section requires the personal consent of the patient and an independent second opinion for certain treatments for mental disorder. It applies to any surgical operation for destroying brain tissue or for destroying the function of brain tissue,[18] and the surgical implantation of hormones to reduce male sex drive.[19] This would prevent these treatments being carried out on an incapacitated patient. We do not consider that this paper is the appropriate place to reconsider the effect of this section.

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[12] See paras. 6.31-6.33 above.

[13] Section 58(1)(b).

[14] Mental Health (Hospital, Guardianship and Consent to Treatment) Regulations 1983, S.I. 1983, No. 893, reg.16(2).

[15] For example, in California attorneys may not consent to E.C.T. (Durable Power of Attorney Act 1983, s.2435). Attorneys and court appointed guardians may not consent to E.C.T. in New Zealand (Protection of Personal and Property Rights Act 1988, s.18). Such a restriction was not favoured in the recent Canadian proposals (for example, Alberta LRI, Report for Discussion No.11, p.71).

[16] Section 2435.

[17] *The Living Will* (1988), p.73.

[18] Section 57(1)(a).

[19] Mental Health (Hospital, Guardianship and Consent to Treatment) Regulations 1983, S.I. 1983, No. 893, reg.16(1).

PART VIII

COLLECTED PROVISIONAL PROPOSALS AND CONSULTATION ISSUES

PART II - THE INCAPACITATED PATIENT

The definition of incapacity

1. **Subject to proposal 4 below, a person should not be regarded as "incapacitated" unless it is established that he or she is suffering from a mental disorder as defined in section 1 of the Mental Health Act 1983.**

2. **A mentally disordered person should be considered unable to take the medical treatment decision in question if he or she is unable to understand an explanation in broad terms and simple language of the basic information relevant to taking it, including information about the reasonably foreseeable consequences of taking or failing to take it, or is unable to retain the information for long enough to take an effective decision.**

We invite views on whether, in the context of medical decision-making, it is necessary to stipulate that the fact that the person's decision differs from that which an ordinary prudent person would take is not, of itself, a sufficient basis for a finding of incapacity (paragraph 2.16).

3. **A mentally disordered person should be considered unable to take the medical treatment decision in question if he or she can understand the information relevant to taking the decision but is unable because of mental disorder to make a true choice in relation to it.**

We invite comment on whether the idea that an apparent consent might not represent a "true choice" might cause any difficulties for those treating mentally disordered patients (paragraph 2.19).

4. **A person, whether or not suffering from mental disorder, should be considered unable to take the medical treatment decision in question if he or she is unable to communicate it to others who have made reasonable attempts to understand it.**

5. **The new jurisdiction should extend to persons aged 16 and over.**

Summary

Any new jurisdiction should be available in respect of people of or over the age of 16 who are:

(1) **suffering from mental disorder within the meaning of the Mental Health Act 1983 and unable to understand an explanation in broad terms and simple language of the basic information relevant to taking the decision in question, including information about the reasonably foreseeable consequences of taking or not taking it, or unable to retain that information for long enough to take an effective decision; or**

(2) **unable by reason of mental disorder within the meaning of the Mental Health Act 1983 to make a true choice in relation to the decision in question; or**

(3) **unable to communicate the decision in question to others who have made reasonable efforts to understand it.**

PART III - THE TREATMENT OF THE INCAPACITATED PATIENT

The patient's "anticipatory decisions"

1. **Legislation should provide for the scope and legal effect of anticipatory decisions.**

2. **If a patient is incapacitated, and subject to the other proposals in Part III of the paper, a clearly established anticipatory decision should be as effective as the contemporaneous decision of the patient would be in the circumstances to which it is applicable.**

The form of anticipatory decisions

We invite comment on whether a model form should be developed and, if so, by whom (paragraph 3.15).

We invite views on the practical implications of oral anticipatory decision-making (paragraph 3.16).

We invite views on whether there should be a rebuttable presumption that a decision is not "clearly established" if it is made in a form which does not meet the statutory requirements (paragraph 3.17).

We invite comment on how copies of a document should be treated (paragraph 3.18).

3. **There should be a rebuttable presumption that an anticipatory decision is clearly established if it is in writing, signed by the maker [with appropriate provision for signing at his direction], and witnessed by [one] person who is not the maker's medical treatment attorney.**

We invite comment on the number of witnesses, and on their qualifications (paragraph 3.19).

4. **An anticipatory decision should be regarded as ineffective to the extent that it purports to refuse pain relief or "basic care", including nursing care and spoon-feeding.**

We invite comment on the content of "basic care" (paragraph 3.25).

5. **An anticipatory decision may be revoked orally or in writing at any time when the maker has the capacity (according to the test proposed in Part III of Consultation Paper No.128) to do so. There should be no automatic revocation after a period of time.**

We invite comment on any practical difficulties the oral revocation of an anticipatory decision may cause (paragraph 3.33).

6. **A treatment provider who acts in accordance with an apparently valid and continuing anticipatory decision should only be liable to any civil or criminal proceedings if he or she does so in bad faith or without reasonable care.**

7. **It should be an offence to falsify or forge an advance directive; or to conceal, alter or destroy a directive without the authority of its maker. These offences should apply to a written revocation of an advance directive as they do to the directive itself.**

A statutory authority to treat

8. **A treatment provider should be given a statutory authority (subject to the other proposals contained in this paper) to carry out treatment which is reasonable in all the circumstances to safeguard and**

promote the best interests of an incapacitated person [or a person whom he or she has reasonable grounds for believing to be incapacitated].

We invite views on whether a treatment provider should only be required to have reasonable grounds for believing the person to be incapacitated (paragraph 3.40).

9. **Unless it is essential to prevent loss of life or irreversible deterioration of health while an issue is referred to a relevant judicial forum, the statutory authority should not permit the carrying out of any treatment contrary to a valid anticipatory refusal by the person who is now incapacitated, a refusal of consent by a person with the authority to do so, or a prohibition by a judicial forum.**

10. **The statutory authority should not permit the taking of any step for which the approval of the judicial forum or some other person is required (see Part VI below) unless that approval has been obtained.**

11. **The statutory authority should not permit the carrying out of any treatment to which the incapacitated person objects, unless such treatment is essential to prevent an immediate risk of serious harm to that person or others.**

A best interests criterion

12. **In deciding whether a proposed medical treatment is in the best interests of an incapacitated person, consideration should be given to:**

(1) the ascertainable past and present wishes and feelings (considered in the light of his or her understanding at the time) of the incapacitated person;

(2) whether there is an alternative to the proposed treatment, and in particular whether there is an alternative which is more conservative or which is less intrusive or restrictive;

(3) the factors which the incapacitated person might be expected to consider if able to do so, including the likely effect of the treatment on the person's life expectancy, health, happiness, freedom and dignity.

13. The interests of people other than the incapacitated person should not be considered except to the extent that they have a bearing on the incapacitated person's individual interests.

The involvement of relatives and others

14. A treatment provider should be under a duty to consult the incapacitated person's "nearest relative" (as defined in the Mental Health Act 1983, section 26) so far as is reasonably practicable, to give that person sufficient information (including information about the patient's condition, the proposed treatment and the reasonably foreseeable consequences of providing or not providing treatment) and to have regard to the views of that person.

15. If the nearest relative is not reasonably available, or is incapacitated, or is unwilling to be consulted, that person should be disregarded for the purpose of determining the identity of the nearest relative.

16. Where the patient has named another person to be consulted about treatment decisions should he or she become incapacitated, the person named should be the "nearest relative" for the purpose of the duty to consult.

17. **Any suitable person who consents to perform the functions of a "nearest relative" for the purposes of the duty to consult may be appointed if the incapacitated person has no "nearest relative", or it is not reasonably practicable to ascertain whether he or she has such a relative, or who that relative is.**

18. **There should be no duty to obtain the consent of another person to the medical treatment of an incapacitated person simply on the basis of a family relationship.**

We invite comment on whether there should be any other grounds for appointing an acting nearest relative (paragraph 3.66).

The liability of treatment providers

19. **A person who provides medical treatment in pursuance of the proposed statutory authority should only be liable to any civil or criminal proceedings if he or she does so in bad faith or without reasonable care.**

PART IV - A JUDICIAL FORUM

A new jurisdiction

1. **There should be a judicial forum with a statutory jurisdiction:**
   (1) to make orders approving or disapproving the medical treatment of incapacitated patients; and
   (2) to make declarations as to the patient's capacity or the scope or validity of the patient's own decisions.

We invite comment on the nature of the judicial forum (paragraph 4.5), and on whether there are any situations where the existence of separate fora for medical

decisions, and other decisions, would cause practical problems (paragraph 4.6). We also invite comment on the relationship of the judicial forum with the High Court (paragraph 4.7).

2. **The judicial forum must be satisfied that the making of an order will bring greater benefit to the incapacitated person than making no order at all.**

We welcome comments on the likely number of applications to the judicial forum (paragraph 4.8).

3. **Any order made should be in the best interests of the incapacitated person, taking into account:**

   (1) the ascertainable past and present wishes and feelings (considered in the light of his or her understanding at the time) of the incapacitated person;

   (2) whether there is an alternative to the proposed treatment, and in particular whether there is an alternative which is more conservative or which is less intrusive or restrictive;

   (3) the factors which the incapacitated person might be expected to consider if able to do so, including the likely effect of the treatment on the person's life expectancy, health, happiness, freedom and dignity, but not the interests of other people except to the extent that they have a bearing on the incapacitated person's individual interests.

4. **An order dealing with a specific issue is to be preferred to the appointment of a proxy, unless there is a need for a continuing authority, and any order should be as limited in scope as possible.**

A range of orders

5. **The judicial forum may make an order giving or withholding approval to the giving, withholding or withdrawal of particular medical treatment in respect of an incapacitated person.**

6. **The judicial forum may make recommendations instead of, or as well as, making an order.**

7. **The judicial forum may make an order requiring the person or persons responsible for the medical care of an incapacitated person to allow some other person, who agrees to take over the care of the incapacitated person, to do so.**

A declaratory jurisdiction

8. **The judicial forum may declare that the person concerned is not incapacitated, either in general or in relation to a particular matter.**

9. **The judicial forum may make a declaration as to whether or not an apparent decision by the patient concerned is "clearly established" and "applicable in the circumstances".**

We invite comment on whether any restrictions should be imposed on the availability of declarations under this jurisdiction (paragraph 4.18).

Appointment of medical treatment proxies

10. **If the judicial forum finds that a single issue order will not be sufficient to benefit the incapacitated person, it may appoint any suitable person who agrees to discharge the duties of a medical treatment proxy for that person. The proxy will have such powers in**

relation to that person's medical treatment as are specified in the order making the appointment.

We invite views on what powers a medical treatment proxy might be granted other than an authority to give or refuse consent to medical treatment, or particular types of medical treatment (paragraph 4.20).

We invite comments on whether it should be possible to appoint a public official as a proxy of last resort (paragraph 4.21).

11. **If a medical treatment proxy has been appointed, a person proposing to provide treatment which is within the scope of the proxy's authority should be under a duty to obtain the proxy's consent, or the approval of the judicial forum, before that treatment is given. There should be no duty to consult the incapacitated person's "nearest relative" in relation to treatments within the authority of the proxy.**

12. **The judicial forum may appoint joint, joint and several, alternate or successive medical treatment proxies.**

13. **The maximum duration of any order or appointment by the judicial forum should be [six or] twelve months in the first instance. Appointments should be renewable for [six or] twelve months at a time.**

We invite comment on the need for a supervisory body, such as the Mental Health Act Commission, in relation to those for whom a medical treatment proxy has been appointed (paragraph 4.23).

14. **A medical treatment proxy must act in the best interests of the incapacitated person, taking into account:**

(1) the ascertainable past and present wishes and feelings (considered in the light of his or her understanding at the time) of the incapacitated person;

(2) whether there is an alternative to the proposed treatment, and in particular whether there is an alternative which is more conservative or which is less intrusive or restrictive;

(3) the factors which the incapacitated person might be expected to consider if able to do so, including the likely effect of the treatment on the person's life expectancy, health, happiness, freedom and dignity, but not the interests of other people except to the extent that they have a bearing on the incapacitated person's individual interests.

15. A medical treatment proxy should be able to recover the expenses of acting.

16. A medical treatment proxy should be able to exercise the rights of the incapacitated person to apply for access to health records under the Access to Health Care Records Act 1990 and the Data Protection act 1984, unless this possibility is specifically excluded by the judicial forum.

17. A medical treatment proxy should have no authority to refuse pain relief or "basic care", including nursing care and spoon-feeding.

18. A medical treatment proxy should have no authority to consent to the carrying out of any treatment contrary to a valid anticipatory refusal by the person who is now incapacitated, or a prohibition by the judicial forum.

19. **A medical treatment proxy should have no authority to consent to the taking of any step for which the approval of the judicial forum or some other person is required (see Part VI).**

20. **A medical treatment proxy should have no authority, unless granted explicitly by the judicial forum, to consent to the carrying out of any treatment to which the incapacitated person objects.**

Applicants

21. **Close relatives, people with whom the incapacitated person has resided, medical treatment proxies or attorneys, personal welfare managers or attorneys, and the person himself or herself, should have a right to apply for an order. The health authority or any person responsible for the incapacitated person's health care should also have a right to apply. Other persons might apply with leave of the judicial forum.**

The authorisation of treatment to which the incapacitated person objects

We invite views on whether any additional procedures or criteria should be included before treatment to which the person objects is authorised (paragraph 4.31).

PART V - ENDURING POWERS OF ATTORNEY

1. **It should be possible for a person to execute an enduring power of attorney giving another person the authority give or refuse consent on his or her behalf to some or all medical treatment in relation to which the donor has become incapacitated.**

2. **The authority of an attorney in relation to a particular medical treatment decision should operate only where the donor is incapacitated in relation to that decision according to the definition of incapacity proposed in Part II of this paper.**

3. **A donor under a medical treatment EPA should always retain the power to do any act, including revoking the EPA, in relation to which he or she has capacity at the time. The definition of incapacity for the purpose of the execution or revocation of a medical treatment EPA should be the same as that proposed in Part III of Consultation Paper No.128.**

We invite views on the content of a standard form. In particular we welcome comment on particular decisions in relation to which the donor must decide whether or not the attorney is to have authority (paragraph 5.7).

4. **The donor's capacity to execute a medical treatment EPA should be certified by a solicitor and a registered medical practitioner at the time of execution.**

5. **A donor should name in a medical treatment EPA the two (or more) persons who are to be notified of its execution and no action should be taken by an attorney under the power unless and until an acknowledgement has been received from the persons so named.**

6. **The donor should be permitted to name someone to confirm his or her incapacity, or to establish any other ground upon which the authority of the attorney depends.**

7. **There should be no requirement that a medical treatment EPA be registered with the Court of Protection, or any other authority, when the attorney believes the donor to be or be becoming incapacitated.**

8. **Only individuals should be capable of being appointed medical treatment attorneys.**

9. **It should be possible for more than one person to be appointed as medical treatment attorneys, whether to act jointly or jointly and severally. It should also be possible for alternate attorneys to be appointed to act in the event of original attorneys ceasing to act.**

10. **It should not be possible to appoint public officials in their official capacity as medical treatment attorneys.**

We invite views on whether there should be any other restrictions on who may be appointed as a medical treatment attorney (paragraph 5.15).

The attorney's powers and duties

11. **A medical treatment attorney should be under no duty to express a view on behalf of the donor. If an attorney chooses to give or refuse consent to a particular medical treatment, he or she must do so in the best interests of the incapacitated person, taking into account:**

(1) the ascertainable past and present wishes and feelings (considered in the light of his or her understanding at the time) of the incapacitated person;

(2) **whether there is an alternative to the proposed treatment, and in particular whether there is an alternative which is more conservative or which is less intrusive or restrictive;**

(3) **the factors which the incapacitated person might be expected to consider if able to do so, including the likely effect of the treatment on the person's life expectancy, health, happiness, freedom and dignity, but not the interests of other people except to the extent that they have a bearing on the incapacitated person's individual interests.**

We invite views on whether it is necessary to require the attorney to consult any other person who has been appointed attorney or manager in relation to the incapacitated person's financial or personal affairs (paragraph 5.17).

12. **If a medical treatment attorney has been appointed, a person proposing to provide a treatment within the scope of the attorney's authority should be under a duty to give the attorney the opportunity to give or refuse consent on the incapacitated person's behalf. There should be no duty to consult the incapacitated person's "nearest relative" in relation to treatments within the scope of the attorney's authority.**

13. **A medical treatment attorney should be able to exercise the rights of the incapacitated person to apply for access to health records under the Access to Health Records Act 1990 and the Data Protection Act 1984, unless this possibility is specifically excluded in the power.**

14. **A medical treatment attorney should have no authority to refuse pain relief or "basic care", including nursing care and spoon-feeding.**

15. **A medical treatment attorney should have no authority to consent to the carrying out of any treatment contrary to a prohibition by the judicial forum, or, unless the power provides otherwise, a valid anticipatory refusal by the donor.**

16. **A medical treatment attorney should have no authority to consent to the taking of any step for which the approval of the judicial forum or some other person is required (see Part VI).**

17. **A medical treatment attorney should have no authority to consent to the carrying out of any treatment to which the incapacitated person objects.**

The powers of the judicial forum

18. **The judicial forum should have power to give effect to the wishes of the donor by curing technical defects in the appointment of a medical treatment attorney, or by appointing a replacement for an attorney who is unable or unwilling to act, and, provided that the donor has so directed, by modifying or extending the scope of the powers granted.**

19. **The judicial forum should have wide powers to revoke the appointment of an unsuitable medical treatment attorney, and to substitute its own decision for the decision of a medical treatment attorney who is not acting in the best interests of the incapacitated person.**

PART VI - INDEPENDENT SUPERVISION OF CERTAIN DECISIONS

Treatments in a "special category"

1. **There should be a "special category" of steps which require the approval of the judicial forum before they are taken in relation to an incapacitated person, except where the step is essential to prevent an immediate risk of serious harm to that person.**

(i) Sterilisation operations

2. **Sterilisation operations, for the purpose of contraception or menstrual management, should be included in the special category.**

(ii) Donation of tissue

3. **An operation to allow donation of non-regenerative tissue, or bone marrow, should be included in the special category.**

(iii) Abortion

We invite views on whether abortion should be included in the special category (paragraph 6.10).

(iv) Withdrawals of nutrition and hydration

4. **The withdrawal of nutrition or hydration necessary for continuation of the patient's life should be included in the special category.**

(v) Medical research

We invite views on whether some types of research should be included in the special category (paragraph 6.14).

(vi) Other decisions

We invite comment on whether any other treatments or any other decisions to withdraw treatment should be included in the special category (paragraph 6.15).

(i) Sterilisation operations

We invite views on whether there are any additional criteria which should be satisfied before approval is given to a sterilisation operation (paragraph 6.20).

(ii) Donation of tissue

We invite views on whether any additional criteria should be established before approval is given to an operation to allow the donation of organs or bone marrow (paragraph 6.21).

(iii) Abortion

We invite views on whether any additional criteria should be established before approval is given to an abortion (paragraph 6.22).

(iv) Withdrawals of nutrition and hydration

We invite views on whether the jurisdiction to make declarations that a particular course is lawful might continue to be the appropriate way to deal with some cases (paragraph 6.24). We also invite views on whether any additional criteria should be established before such a declaration is made, or approval is given to the withdrawal of artificial nutrition and hydration (paragraph 6.25).

(v) Medical research

We invite comment on whether any additional requirements should be satisfied before beneficial treatment is provided which has an additional research objective (paragraph 6.26).

5. Non-therapeutic research or experiments on an incapacitated subject should not be lawful unless:

(a) the research is into the mental disorder, or other incapacitating condition, suffered by the subject;

(b) the research entails only an insubstantial foreseeable risk to the subject's physical or mental health. Views are invited on what should constitute an insubstantial risk;

(c) the research has been approved by the appropriate local research ethics committee;

(d) the consent of a medical treatment proxy or attorney appointed with authority to give such consent has been obtained, or (if no such person has been appointed) the subject's nearest relative has agreed in writing;

(e) before seeking such agreement or consent, the purpose of the research, the procedures to be used and the foreseeable risk to participants, have been explained;

(f) the subject does not object to participating in the research, and has made no anticipatory decision refusing to participate.

Other safeguards

6. **Certain treatment decisions should require a confirmatory second opinion by an independent registered medical practitioner.**

We invite comment on the situations to which this requirement should apply (paragraph 6.33).

7. **Certain treatment decisions should require the approval of an independent person or body appointed for this purpose.**

We invite views upon the treatment decisions to which this requirement should apply (paragraph 6.34).

PART VII - TREATMENT FOR MENTAL DISORDER

1. **The proposals in this paper should apply to treatment for mental disorder.**

2. **The proposals in this paper should not operate in relation to the treatment for mental disorder of an incapacitated person who is subject to Part IV of the Mental Health Act 1983.**

We invite views on whether some of the safeguards outlined in Part VI above should be applied to particular treatments for mental disorder (paragraph 7.11). We also invite views on whether any treatments for mental disorder should be excluded from the authority of medical treatment attorneys or proxies (paragraph 7.12).

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